

The Roadmap for European CAM Research

A pan-European research network for Complementary and Alternative Medicine (CAM)

Final Report of CAMbrella Work Package 4 (leader: George Lewith)

CAM use in Europe – The patients' perspective. Part II: A pilot feasibility study of a questionnaire to determine EU wide CAM use

Susan Eardley, Felicity L Bishop, Francesco Cardini, Koldo Santos-Rey, Miek C Jong, Sorin Ursoniu, Simona Dragan, Gabriella Hegyi, Bernhard Uehleke, Jorge Vas, Ovidiu Jupaneant, Maria Caterina Citro, Vinjar Fønnebø, Sara A Quandt, George Lewith

This report is part of a collection of reports created as deliverables of the project CAMbrella funded by the 7th Framework Programme of the European Commission (FP7-HEALTH-2009-3.1-3, Coordination and support action, Grant-Agreement No. 241951, Jan 1, 2010 – Dec 31, 2012); Coordinator: Wolfgang Weidenhammer, Competence Centre for Complementary Medicine and Naturopathy (head: Dieter Melchart), Klinikum rechts der Isar, Techn. Univ. Munich, Germany





Susan Eardley¹, Felicity L Bishop¹, Francesco Cardini², Koldo Santos-Rey³, Miek C Jong⁴, Sorin Ursoniu⁵, Simona Dragan⁶, Gabriella Hegyi⁷, Bernhard Uehleke^{8,9}, Jorge Vas³, Ovidiu Jupaneant⁶, Maria Caterina Citro^{10,11}, Vinjar Fønnebø¹², Sara A Quandt¹³, George Lewith¹:

CAM use in Europe – The patients' perspective. Part II: A pilot feasibility study of a questionnaire to determine EU wide CAM use

Final Report of CAMbrella Work Package 4 (leader: George Lewith)

2012

Contact:

University of Southampton, UK, Primary Care and Population Science, Complementary & Integrated Medicine Research

http://www.southampton.ac.uk/camresearchgroup
e-mail:

jc2@soton.ac.uk, glewith@scmrt.org.uk

¹ Complementary and Integrated Medicine Research Unit, University of Southampton, UK

² Healthcare and Social Agency of Emilia Romagna Region, Bologna, Italy

³ Andalusian Health Service, Pain Treatment Unit, Doña Mercedes Primary Care Centre, Dos Hermanas, Spain

⁴ Louis Bolk Institute, Driebergen, The Netherlands

⁵ Department of Public Health, Victor Babes University of Medicine and Pharmacy, Timisoara, Romania

⁶ Department of Preventive Cardiology, Victor Babes University of Medicine and Pharmacy, Timisoara, Romania

⁷ PTE ETK Komplementer Medicina Tanszék, University of Pecs, Hungary

⁸ Institute of Complementary Medicine, University Hospital Zurich, Switzerland

⁹ University of Health and Sports, Berlin, Germany

¹⁰ Department of Obstetrics and Gynecology, Arcispedale Santa Maria Nuova-IRCCS, Reggio Emilia

¹¹ University of Modena and Reggio Emilia, Italy

¹² National Research Center in CAM (NAFKAM), Institute of Community Medicine, University of Tromsø, Norway

¹³ Dept of Epidemiology and Prevention, Wake Forest School of Medicine, Winston-Salem, NC, USA

Susan Eardley, Felicity L Bishop, Francesco Cardini, Koldo Santos-Rey, Miek C Jong, Sorin Ursoniu, Simona Dragan, Gabriella Hegyi, Bernhard Uehleke, Jorge Vas, Ovidiu Jupaneant, Maria Caterina Citro, Vinjar Fønnebø, Sara A Quandt, George Lewith: CAM use in Europe – The patients' perspective. Part II: A pilot feasibility study of a questionnaire to determine EU wide CAM use

Final Report of CAMbrella Work Package 4 (leader: George Lewith)

CAMbrella – A pan-European research network for Complementary and Alternative Medicine (CAM) The goal of this collaboration project was to look into the present situation of CAM in Europe in all its relevant aspects and to create a sustained network of researchers in the field that can assist and carry through scientific endeavours in the future. Research into CAM – like any research in health issues – must be appropriate for the health care needs of EU citizens, and acceptable to the European institutions as well as to national research funders and health care providers. It was CAMbrella's intention to enable meaningful, reliable comparative research and communication within Europe and to create a sustainable structure and policy.

The CAMbrella network consists of academic research groups which do not advocate specific treatments. The specific objectives were

- To develop a consensus-based terminology widely accepted in Europe to describe CAM interventions
- To create a knowledge base that facilitates our understanding of patient demand for CAM and its prevalence
- To review the current legal status and policies governing CAM provision in the EU
- To explore the needs and attitudes of EU citizens with respect to CAM
- To develop an EU network involving centres of research excellence for collaborative research.

Based on this information, the project created a roadmap for research in CAM in Europe. The roadmap sums up and streamlines the findings of the whole project in one document that aims to outline the most important features of consistent CAM research at European level.

For other reports of the CAMbrella project which are also available on https://phaidra.univie.ac.at/ see the additional information on the description data (meta-data) of this report.

Acknowledgements

We would like to thank Klaus von Ammon, Meike Dlaboha, Seamus Connolly, Sabine Zopf, Wolfgang Weidenhammer, Åsa Sohlén, Jackie Burnham, Solveig Wiesener, Tania Salandin, Stefania Florindi, Mirela Cioara, Glen Harding, Marcelle Weisfelt, Bernadette Krom, Anna Pfeiffenroth, Krisztina C. Sutortoki, Germaine Savoiu, Ellen Wilson, Nick Girling, and Corina Guethlin for their contributions to this report.

Preface

According to the Description of Work of the CAMbrella project Work Package 4 on "CAM use – the patients' perspective" encompassed the following tasks:

- Task 4.1: To address the prevalence of CAM use in Europe: We will take into account regional and national variations, and create a summary of current information about prevalence of CAM use and its trajectory.
- Task 4.2: To identify the major conditions treated with CAM: Based on existing literature as well as suggesting future research strategy to overcome relevant "evidence gaps" we will identify the major conditions treated with CAM. To explore the reasons why patients choose CAM: The survey material and existing databases will need to be systematically reviewed in order to answer this question.
- Task 4.3: To identify a standardised questionnaire for CAM use in at least three European languages that will provide a consistent, EU approach to a central, widespread limited range of CAM.

The report of Work Package 4 was split into two parts I and II (present report): The present **part II** is addressing a consensus-based and piloted questionnaire to assess the prevalence of CAM use in Europe (see task 4.3 above).

The report on objectives, methodology and findings regarding "A systematic literature review of CAM prevalence in the 27 EU member states and 12 associated countries" (see tasks 4.1 and 4.2 above) is presented in terms of **part I** of the WP4 report (also available on Phaidra).

Table of content

Exec	utive Summary	7
1.	Introduction	8
2.	Methods	10
2.1	Translation of the I-CAM-Q	10
2.2	Pilot feasibility study	11
2.2.1	Participants	11
2.2.2	2 Recruitment	12
2.2.3	3 Questionnaires	12
2.2.4	Procedure	13
2.2.5	5 Data Analysis	14
3.	Results	16
3.1	Translations	16
3.2	Pilot study - qualitative data analysis	17
3.2.1	Terminology: names of health care practices and practitioners	18
3.2.2	2 Understanding categories	19
3.2.3	Reasons for use	20
3.2.4	1 'Other' options	21
3.2.5	5 Layout	21
3.2.6	Memory and choosing response options	22
3.3	Pilot Study – quantitative data analysis	23
3.3.1	Demographic and study sample characteristics of the participants	23
3.3.2	Overview of Missing Data across Questions	25
3.3.3	Compliance with Instructions about Question Routing	25
3.3.4	Missing Data for Prevalence of Use Items	26
3.3.5	Missing Data for Frequency of Use Items	26
3.3.6	Missing Data and Compliance with Instructions for Reasons for Use Items	27
3.3.7	7 Missing Data for Helpfulness Items	28
3.3.8	Web-Based Delivery: The Dutch Pilot	29
4.	Discussion	31
4.1	Summary	31
4.2	Translations	31
4.3	Pilot study	32
4.3.1	Demographic of the participants	32
4.3.2	•	
4.3.3	Strengths and limitations (of our pilot)	36
4.3.4	Recommendations	37
4.4	Conclusions	
	References	39
	Appendix	41

Executive Summary

Objective

We aimed to translate a pre-existing 'CAM use' questionnaire into at least 3 EU languages. We further aimed to perform mixed methods pilot studies in these countries to determine its feasibility to provide a comparative, standardised EU questionnaire for use by healthcare providers, policy makers and purchasers throughout Europe.

Methods

Work package members made initial translations of the questionnaire and produced lists of terms and wording that had different meanings in their countries. The group discussed the contentious terms and agreed to the use of comparable terminology for each country whilst maintaining the essence of the interventions being measured. Final translations were completed and the questionnaires were then piloted on convenience samples of 50 participants per country. Of each group of 50 people, 40 completed the questionnaire on their own and 10 completed the questionnaire in the presence of an interviewer who recorded the discussion and used a cognitive interview technique (think aloud) to enable participants to talk about the questionnaire as they answered it. Each country inputted their own quantitative data into a SPSS data file and transcribed their own interview data analysing the transcripts qualitatively to identify potential difficulties with the questionnaire. Qualitative summaries of the transcripts (in English) and the quantitative SPSS data files were sent to Southampton for data pooling.

Results

The I-CAM-Q was translated into four EU languages (Italian, Spanish, Dutch and Romanian) with minor amendments of terminology to suit individual country requirements. Participants were recruited across a variety of educational backgrounds, self-rated health status and CAM experiences. The pilot studies were completed and data was pooled by the coordinating office in Southampton. The qualitative analysis identified common problems across countries, including the layout (seen as difficult to follow), terminology (often misunderstood or unfamiliar) and the response options (perceived as unclear or inappropriate, miss-used and creating difficulties in identifying non CAM users). The quantitative analysis confirmed that a substantial minority of respondents failed to follow the instructions on the questionnaire and showed that some questions had worryingly high rates of missing data.

Conclusion

As a self-complete questionnaire, the I-CAM-Q has low face validity, low acceptability, and is likely to produce biased estimates of CAM use if used in England, Romania, Italy, Netherlands or Spain. Further work is required to develop the layout, terms, some response options and instructions for completion.

1. Introduction

The use of complementary and alternative medicine (CAM) has increased considerably in recent years [1-5] but it's difficult to compare prevalence reliably across EU member states due to the differing definitions of CAM [6], response time frames over which CAM use is measured and disease versus general population samples. Reliable and accurate information about CAM prevalence is important in order to understand the issues surrounding its safe provision to EU citizens. Health care policy-makers need to know about the popularity of CAM in order to determine needs for publicly funded practitioner training/regulation and service provision. Medical practitioners need to know what proportion of their patient group is likely to be using CAM in addition to conventional medicines, to inform their own practices and training needs. Researchers need to know which forms of CAM are most popular for which conditions in order to target limited research resources appropriately. To date, no questionnaire specifically measuring core components of CAM use has been validated for use across EU countries.

<u>Background</u>

The International Questionnaire to measure use of Complementary and Alternative Medicine (I-CAM-Q) constitutes a good candidate for an international standard measure of CAM use. It was developed collaboratively by a group of international experts at a workshop held at the University of Tromsø, Norway [7]. In formulating the items, the experts explicitly aimed for the resulting questionnaire to be usable in different languages and populations. To facilitate this, the questionnaire has a number of core items (which must be present on all versions of the questionnaire) and the option to add a few extra items (to be specified on local versions of the questionnaire if necessary to assess the most common forms in CAM in a particular context). The questionnaire comprises 4 separate sections as follows: Use of Providers (Question 1), Use of Physician-Delivered Therapies (Question 2), Use of CAM Products (Question 3), and Use of Self-Care Practices (Question 4). Respondents are asked to indicate whether or not they used a particular provider or health care practice/product, the number of times they used the service or product in a given time period, their reasons for use and lastly to indicate how helpful the practice or product had been (see Appendix).

To date, no psychometric evaluations of the I-CAM-Q have been published, although it has been used in a study examining the relationship between spiritual/religious values, use of and satisfaction with CAM [8] and in a study to assess the relationship between health literacy and CAM use [9]. The I-CAM-Q has also been used in studies of CAM prevalence which are currently in submission: a study of cancer patients in the USA [10], a pilot study using cognitive interviews in Germany [11] and a study to compare two questionnaires for eliciting CAM use in a multi-ethnic US population of older adults [12] (communication). A

fourth study of Hungarian military use of acupuncture and other CAMs, undertaken by a WP4 CAMbrella member has also been performed and is currently in submission [13] but we were unable to use the data in this study as it had already been collected prior to the development of our protocol and was therefore not compatible.

The primary aims of this study were to translate the questionnaire into at least 3 European languages and then to generate preliminary evidence concerning the face validity, acceptability, and basic psychometric characteristics of the I-CAM-Q across these different European populations. We aimed to establish these basic properties of the I-CAM-Q both for people who have and for people who have not used CAM. This was important because the I-CAM-Q needs to be completed reliably by both users and non-users in order to produce accurate estimates of the prevalence of CAM use in the population. If non-users tend not to complete the questionnaire at all or produce high levels of missing data, then the prevalence of CAM use could be overestimated. Conversely, if CAM-users are unable to report the full extent of their CAM use, then the extent of CAM use in the population could be underestimated.

Objectives

The objectives across the participating countries were:

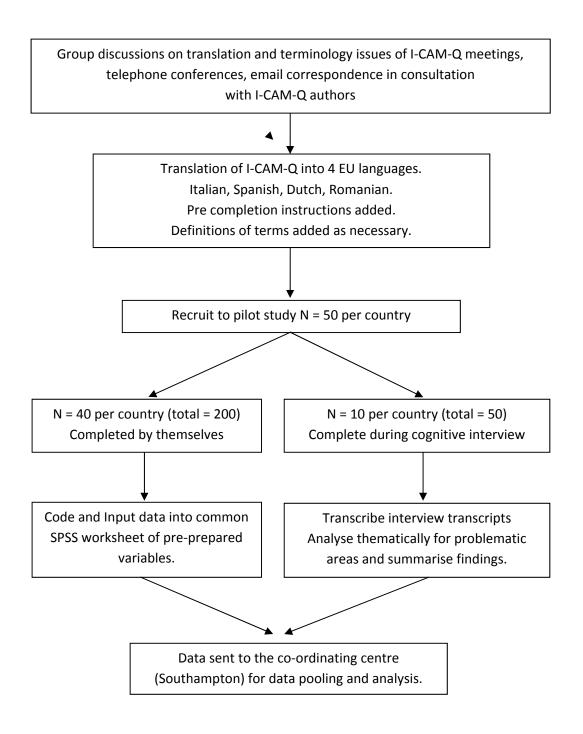
- To identify any problematic items on the I-CAM-Q (i.e. items which are likely to be misinterpreted by respondents who (a) have or (b) have not used CAM), and to suggest improvements.
- To identify any problematic response options on the I-CAM-Q (i.e. response options which are likely to be misinterpreted by respondents who (a) have or (b) have not used CAM), and to suggest improvements.
- To identify any problems with the layout of the I-CAM-Q (from respondents' perspectives) and to suggest improvements.
- To identify the acceptability of the I-CAM-Q when it is administered to respondents who have and have not used CAM.
- To evaluate the feasibility of self-complete delivery of the I-CAM-Q by assessing missing data rates and compliance with instructions.

2. Methods

2.1 Translation of the I-CAM-Q

A PDF copy of the I-CAM-Q from the original paper was distributed to members of WP4 who were native speakers of Spanish, Italian, Romanian and Dutch. Each separate item on each of the four questions was given a corresponding number to co-ordinate effective discussion regarding the translation of specific terminology.

Figure 1. Flow Chart of study protocol



Translators from each country generated a list of issues and difficult terms encountered during the translations. These lists were compared and discussed in order to achieve a group consensus on terminology without changing the essence of the questionnaire itself. The translation processes were guided by the EORTC quality of life group, translation procedure [14] whereby the questionnaire was translated from English into an EU language by a native speaker of that EU language and then back translated by a native English speaker into English. It was agreed that specific instructions on how to complete the questionnaire were necessary for some countries and these were inserted at the start of the questionnaire. Definitions were added by some countries when terminology was deemed likely to be poorly understood.

The authors of the I-CAM-Q (personal communication I-CAM-Q teleconferences/emails) were consulted in relation to the addition of demographic questions, a set of instructions that were adaptable and relevant to country national guidelines, a specific definition for the term *spiritual healing* and for clarification regarding defining terms where they may have been misunderstood in some countries.

2.2 Pilot feasibility study

We aimed to pilot the questionnaire in the UK and at least 3 other European countries. A draft protocol for the pilot study was circulated, commented on and agreed by all participating countries. Ethical approval was sought and granted in countries where it was a requirement namely the UK, Italy, Spain and Romania (Appendix A, 1–4).

The pilot study incorporated two main methods: 1) a pilot test of the self-complete version of the I-CAM-Q, and 2) cognitive interviews about the I-CAM-Q. The pilot-test of the self-complete version primarily addressed objective 5. The cognitive interviews primarily addressed objectives 1, 2, 3, and 4. Cognitive interviews are commonly used in questionnaire design to assess respondents' comprehension of questions and the cognitive processes that underpin their responses¹.

2.2.1 Participants

Each participating research centre aimed to recruit 50 respondents to complete the I-CAM-Q. Inclusion criteria were: adult (aged 16 years and over), capable of giving informed consent. A purposive sample of volunteers was recruited to include some adults with each of the following characteristics:

1. People who were heavy CAM users (currently use multiple CAM forms).

¹ Collins, D. (2003). Pretesting survey instruments: An overview of cognitive methods. Quality of Life Research, 12, 229-238

- 2. People who were light CAM users (currently or recently use one or two CAM forms).
- 3. People who have never used CAM.
- 4. People of average or below average reading ability.
- 5. People with a chronic illness.
- 6. People without a chronic illness.

It was desirable to recruit some respondents with each of those characteristics because if the I-CAM-Q was used to survey the general population about CAM use in the future, it should have face validity and be acceptable to a wide range of people. A sample size of 50 per research centre was considered sufficient to assess the face validity and acceptability of each different language-version of the I-CAM-Q, and to assess rates of missing data and compliance with instructions overall and for each version.

2.2.2 Recruitment

Each research centre aimed to recruit 40 respondents to complete the questionnaire alone and returned it by post or by hand. Each research centre also aimed to recruit 10 respondents to complete the questionnaire in the presence of a researcher. Respondents were recruited from convenient sources for each research centre:

- In the UK a local CAM practice, a University primary care department and local community/leisure centres
- In Spain the Reina Sofía University Hospital (Córdoba), a private rehabilitation office in Seville and a public primary care office in Ronda, Malaga.
- In Italy the Obstetrical and Gynaecological Department of S. Maria Nuova Hospital of Reggio Emilia.
- In The Netherlands several CAM practices via the National Organisation of CAM physicians.
- In Romania a local CAM practice, The Clinic of Cardiovascular Prevention and Rehabilitation and the Victor Babes University of Medicine and Pharmacy, Timisoara.

2.2.3 Questionnaires

Respondents were asked to complete the following measures; the English language version of each is appended (<u>Appendix B</u>):

- 1. The I-CAM-Q which comprised four pages of questions about utilisation of conventional medicine and CAM (<u>Appendix B1</u>). Italian, Spanish, Romanian and Dutch versions of the I-CAM-Q may also be found in the appendix (<u>Appendix B2-5</u>).
- 2. A short questionnaire consisting of open-ended questions assessing the acceptability of the I-CAM-Q (Appendix B8).

3. A short questionnaire on socio-demographic characteristics and health status (Appendix B7).

2.2.4 Procedure

The method of identifying and approaching potential respondents was adapted by each research centre. In the UK, potential respondents were offered either a Self-Complete Invitation Pack or a Cognitive Interview Invitation Pack.

<u>Self-Complete Study</u>

The Self-Complete Invitation Pack (<u>Appendix C</u>) contained an invitation to complete and return a questionnaire by post or by hand (respondent's choice). The pack included the following documents:

- a. Invitation Letter A (incorporating participant information leaflet).
- b. One copy of each of the questionnaires listed above ("Questionnaires").
- c. A freepost reply envelope.

Completion and return of the questionnaire was sufficient to indicate consent. This was explained on Invitation Letter A. It was anticipated that it would take respondents no more than 20 minutes to complete the study materials.

The Dutch centre piloted a web-based I-CAM-Q which differed in important ways from the self-complete version piloted by the other centres. The web-based delivery allowed the researchers greater control over how respondents used the questionnaire. Question routing was automatically controlled, meaning that each respondent only saw those questions that were appropriate to themselves. For example, only those respondents who reported having seen a physician in the past 12 months were asked Question 2. Respondents who reported not having seen a physician in the past 12 months was not shown any Question 2 items. Furthermore, the programme was designed to not accept multiple reasons for use and to only allow completed questionnaires to be submitted. This web-based delivery method was thus designed to ensure respondents complied with questionnaire instructions and provided complete responses.

Cognitive Interview Study

The Cognitive Interview Invitation Pack (<u>Appendix D</u>) contained an invitation to meet a researcher and talk to them about the questionnaire. The pack included the following documents:

a. Invitation Letter B (incorporating participant information leaflet) (Appendix D1).

On receiving a completed reply slip, the researcher telephoned the respondent to arrange a mutually convenient date and time to conduct the cognitive interview.

Cognitive interviews were conducted in the UK at the University of Southampton, in Spain at a pain treatment unit (Dos Hermanas), in Italy at the Obstetrical and Gynaecological Department of S. Maria Nuova Hospital of Reggio Emilia, in The Netherlands at the Louis Bolk Institute and in Romania at the Victor Babes University of Medicine and Pharmacy Timisoara.

All centres followed the same procedure for conducting the cognitive interviews. Before commencing the cognitive interview the researcher explained the study to the respondent, took written informed consent (Appendix D2), and used a warm-up exercise to familiarise respondents with the act of speaking their thoughts aloud. The cognitive interview then commenced. The researcher elicited respondent's immediate reactions (think aloud) as they first saw and then completed the I-CAM-Q. When the respondent had completed the I-CAM-Q the researcher asked additional probing questions to elicit further detail of the respondent's understanding of and reaction to the I-CAM-Q. The interview topic guide which may be found in the appendix (Appendix D3) was used flexibly. Cognitive interviews were audio-recorded.

2.2.5 Data Analysis

Qualitative - Interview Data

Each centre transcribed their cognitive interviews and extracted data based on any problematic issues regarding terminology or layout of the questionnaire and provided an English summary to the co-ordinating centre (Southampton). In producing their summaries, researchers collated and reviewed talk (and written comments on the questionnaires) pertaining to each core item, each response option of the I-CAM-Q, and general features of the I-CAM-Q including the instructions, format, and layout. Similar comments were grouped together (categorised) to identify misinterpretations and other problematic or difficult features of the questionnaire. Possible solutions were suggested. The co-ordinating centre then collated these findings and circulated the results to all centres for feedback and to ensure an accurate representation of all key issues had been achieved. Illustrative verbatim quotes presented below were selected from the UK interviews as these were readily available in English (other centres transcribed their interviews in the original language and provided summaries in English) (Appendix E2-5).

Quantitative - Questionnaire Data

Participating countries were given data coding guidelines and a pre-prepared SPSS spread sheet containing the required variables. Blanks were coded such that it was possible to distinguish between items that had been appropriately left blank (e.g. when respondents reported no use of a particular modality they were not required to report any further details about that modality) and missing data, defined as those items which should have been completed but were not (e.g. when respondents reported using a particular modality but failed to then report the required further details such as frequency of use, reasons for use, satisfaction with use). Textual data (i.e. written answers to open-ended questions) were typed into a Word document and incorporated into the analysis of the Interview Data.

Each centre inputted their questionnaire data into SPSS or other available statistical package. The co-ordinating centre (Southampton) collated all of the data into a single data-file in SPSS version 19. Where countries over-recruited (UK, Netherlands), a random sample of 50 respondents was selected for inclusion in the quantitative analysis to ensure the findings were not overly influenced by one language-version of the I-CAM-Q.

Basic descriptive statistics were produced (frequency counts, percentages, means, standard deviations, as appropriate) to describe respondents' characteristics and responses to each item on the I-CAM-Q. Descriptive statistics were produced for the entire sample and for each country separately.

In accordance with objective 5, the main quantitative analysis focused on two issues:

- 1. The extent to which respondents followed the instructions on the I-CAM-Q and
- 2. The extent of missing data

The extent to which respondents followed instructions were assessed with reference to two key instructions:

- 1. To skip Question 2 if you respond 'no' to the Question 1 item "have you seen a physician in the last 12 months". We calculated the number of times answers to Question 2 items were provided by respondents who should have skipped this question.
- 2. To select one reason for use. We calculated the number of times that respondents reported using a CAM modality and then either failed to select any reasons for use and/or selected more than one reason for use. These frequency data were then expressed as percentages of the expected number of responses. This data was then considered in conjunctions with the qualitative data to enable us to create the best possible explanation for our observations.

The total missing data was summed across all commensurate items within each I-CAM-Q Question, for each different language-version of the I-CAM-Q. For example, the total number of missing responses on the prevalence of use question ('have you used [CAM modality] in the past 12 months') was summed for all of the named practitioners in Question 1. This was

then repeated three times, i.e. for the equivalent items about use of a) the named physiciandelivered CAM therapies in Question 2, b) CAM products in Question 3, and c) CAM self-care modalities in Question 4. The total number of missing responses was then expressed as a percentage of the total expected number of responses.

The quantitative data from the Dutch pilot are presented separately because the Dutch I-CAM-Q was delivered using a web-based questionnaire designed to ensure respondents complied with questionnaire instructions and provided complete responses.

Prevalence rates are only reported to describe our sample characteristics; the extent of missing data and the results taken in conjunction with the information from the cognitive interviews suggest further development work is needed to ensure the validity and reliability of the I-CAM-Q and the accuracy of the data it produces.

3. Results

3.1 Translations

The WP4 group members discussed each set of translation and terminology problems by telephone conference, email and at group meetings between March 2010 and March 2011 and translations were completed by March 2011 according to the EORTC procedure [14].

There was considerable debate about the local variation of therapies available however it was agreed that all items on the original questionnaire would be included as published and in making translations to other languages, items would be translated in a way that captured the essential aspects or skill set of the practice. For example, the term *chiropractic* does not exist in Romania and would have been poorly understood therefore the term was translated as *Manual Therapist*. The term *herbs* was translated to *medicinal plants* for the Spanish questionnaire as it was a more understandable term in that country.

After discussion with the authors of the I-CAM-Q, it was agreed that items would not be left off, even if it were suspected that all respondents in a particular country would respond "no". The Work Package Members were asked to add any practice or remedy about which they had a special interest or which was common to their country but not included on the original I-CAM-Q in the "Specified Option". For example in the Netherlands, *Anthroposophic Medicine* is well known whereas *osteopathy*, a commonly available therapy in other countries, is not popular.

The term *Spiritual Healing* was the most contentious term due to it being perceived as a matter of religion rather than health care in some EU countries and may have been considered by patients to be a church based healing in other countries. In the development

of the original I-CAM-Q questionnaire the term *Spiritual Healing* was meant to be different from *church based healing* but respondents were allowed to put church based healing under spiritual healing if that was what it meant to the person [15]. The group agreed to explain the term to the respondents in a way that was relevant to each individual country for example, in Spain, the term was defined as '*a technique like Reiki*'.

A set of instructions aimed to increase ease of completion for the respondents was circulated by the authors of the I-CAM-Q [16], agreed by the group, translated as necessary and placed at the beginning of the questionnaire. Definitions of terms were added by countries where WP4 members considered it necessary.

Italy added definitions to *Spiritual Healing* and *Traditional Healing Ceremony* and Romania added definitions to *Spiritual Healing* and *Chiropractor* as may be seen on the appended translated questionnaires.

A set of demographic questions were agreed and added at the end of the questionnaire (Appendix B7).

A copy of each translated I-CAM-Q used in this study may be found in the appendix (<u>Appendix B1–5</u>). We include the Hungarian translation for completeness (<u>Appendix B6</u>).

3.2 Pilot study - qualitative data analysis

The cognitive interviews in each country were conducted between June 2011 and December 2011. The table below identifies the shorted, longest and average interview times.

<u>Table 1</u>: Length of interview time by country (minutes, seconds)

Country	Shortest interview	Longest interview	Mean
Italy	12 min	17 min	18 min 30 sec
Netherlands	7 min	20 min	10 min
UK	9 min 14 sec	27 min 28 sec	12 min 35 sec
Spain	8 min 50 sec	15 min 25 sec	11 min 10 sec
Romania	9 min17 sec	20 min 59 sec	13 min 23 sec
Combined country			13 minutes

Each country's individual summary may be found in the appendix (<u>Appendix E1-5</u>). Overall, six main problematic areas of the questionnaire were identified and are described below.

3.2.1 Terminology: names of health care practices and practitioners

In questions 1 and 2 participants were asked if they had seen any of a list of health care providers. Respondents in each country did not know the meaning of some of the terms. In questions 3 and 4, participants were asked if they had used vitamins, remedies or self-help practices and again respondents in each country did not know the meaning of some of the terms. The box below contains the 24 terms that were problematic and this theme may be summarised in the following quote from a UK interviewee.

'that I'm not familiar with, {the terms} cause I didn't know what they were.'

Physician, homeopath/homeopathy, chiropractor, acupuncture, herbal medicine/herbalist, spiritual healer, manipulation, health condition, complementary treatments, well-being, self-help practices, Qi Gong, Tai Chi, relaxation, meditation, visualisation, acute/chronic, specified option/other, vitamins & minerals

In the UK, 9 participants were unfamiliar with the term *physician* (Q1) with 2 suggesting that it was confusing because it's in American usage, not British. One participant suggested that it was an ambiguous term open to individual interpretation and indeed an example of this was where another respondent had seen a nurse and didn't know whether to record the visit under physician or 'other'.

The terms *homeopathy/homeopath, herbs/herbalist* and *acupuncture* were not known or not differentiated by interview respondents in the UK, Spain or Italy and yet these are arguably the more prevalent CAM interventions.

'some of, some of it, homeopathy I don't even know what that is, so...urm...I guess I was a bit stumbled by that...'

Similarly, *chiropractic* and *manipulation* was not known by some interview respondents in the UK and Spain. In the UK, one person did not understand the term *chiropractor* yet this respondent was recruited to the study at a chiropractor's clinic further suggesting that some people are generally unaware of the formal terminology for CAM.

The term *spiritual healing* was not recognised at all in Spain and in Italy respondents all had to read a definition in order to answer the question.

Question 3 asked participants to record the **supplements and remedies** they were taking. Respondents in the Netherlands, the UK and Romania who were taking a **homeopathic** or **herbal** remedy did not know the name of their remedy or were not sure whether it was **homeopathic** or **herbal** or should be placed in the **'other'** category and so had difficulty providing answers to this question. For example, in the Netherlands respondents using Tea

Tree Oil, linseed oil, valerian, propolis and echinacea didn't know whether they were *herbal* or *homeopathic* and a quote from a UK respondent demonstrates a similar issue.

'Erm I will put under herbs and herbal medicine, I'm not sure if that's where you want to put it under. But erm the bach flower remedy...'

At least 1 interviewee from each of the Netherlands, the UK, Italy and Romania took more than 3 *supplements* and therefore didn't know which ones to write on the 3 spaces allowed in the questionnaire. The questionnaire asks how helpful a particular remedy was but across countries, the respondents were unable to decide how helpful the products were often because they took them as a preventative measure for example in Romania one respondent was taking a herbal tea as a preventative and therefore could not say how helpful it was.

Across all countries some of the self-help items in question 4 were confused or not recognised. The term *Qigong* proved the most problematic term with few people in any country knowing what it was and this is illustrated by the following two UK quotes.

'...what the hell's Qigong?...what's Qigong?...Qygong? keygong?'

'urgh...I don't even know how you say that so I'm gonna tick no for that one...'

A recurring theme that emerged from all countries was that **self-help techniques** were used as preventative measures and therefore it was not easy for respondents to say how helpful they were.

3.2.2 Understanding categories

A number of participants from the UK suggested that some terms were too broad and categories were not clearly specified

'The terms used e.g. physician, spiritual healer are quite ambiguous and open to individual interpretation and thus you should make this more clear. Also you could specify with 'herbalist' what you mean 'e.g. Chinese, western' to ensure you are clear about what you are trying to collect.'

This was true even of the overarching category 'complementary medicine': several participants (from the UK, Netherlands and Spain) did not know what this meant and others questioned whether specific therapies that they had used (e.g. hypnotherapy) should be included within this category.

'I don't really know what complementary treatments are...if I'm honest...'

With regard to **self-help practices**, apart from many people not understanding the terminology, participants in the UK, Italy and the Netherlands asked if sports and exercise or eating healthy food, voluntary work or art were included in this category. Participants in all countries confused the terms **visualisation** and **relaxation**, a distinction could not be made between them and these terms together with **breathing exercises**, **meditation** and **yoga** were thought to be synonymous by participants who consequently found it difficult to answer these questions.

3.2.3 Reasons for use

The I-CAM-Q asks people to state the type of illness they used a CAM modality for. Respondents are asked to select from the following options: acute illness, chronic illness, wellbeing, any other reason (which they can then write on the questionnaire). The use of the terms acute and chronic illness were noted as confusing to respondents from the UK, the Netherlands and Italy. In the Netherlands one person had complaints that lasted more than 1 month but she personally did not count this as chronic. When asked for her definition of chronic it was 'something like diabetes' which might suggest that for her, chronic means 'serious' or something that lasted for years. Another Dutch respondent said that they had had diabetes for 1 year but they didn't consider that chronic. In Italy, respondents asked if a chronic illness had to last a long time e.g. years and be something like diabetes or could it be just weeks like an infection. Some respondents did not know how serious a problem had to be in order to be called an illness for example a sore throat or flu and one respondent asked 'could a headache that lasted one day be an acute illness'?. In the UK acute and chronic conditions were also misunderstood in terms of the length of time to be considered one or the other. One participant was not sure what a chronic illness was and another wondered if a muscular strain was an acute illness. One person asked the interviewer if a slipped disc was a health condition.

'would you consider a slipped disc a health condition or is it more of an injury'

When the questionnaire asked about the main reason for the visit to a practitioner people often ticked more than the required 1 option. This was noticed several times in the UK and Spain. Participants in the UK suggested that the term **well-being** was itself too broad with one participant asking if it was specifically about psychological issues of anxiety or depression. One respondent in the Netherlands said that 'wellbeing had different meanings for different people'.

3.2.4 'Other' options

The **specified option/other category** was frequently misunderstood by participants in the UK and Italy who either thought it was a space to put an illness or didn't know what it referred to at all. In question 3, one UK respondent recorded the name of their biomedical drug under 'specified option'.

'Though what's this with specified option and other option, other please specify. What are the two different things?'

3.2.5 Layout

A number of UK participants determined the layout as 'unclear' and 'muddy' and having 'quite a lot on the page'. They frequently missed completing sections because they didn't see something they ought to have completed. This problem was also identified in Spain and the Netherlands and in Romania where the font size was considered too small.

'oh I didn't even read it. There you go. I just didn't even read it'

The vertical columns at the top of each page proved highly unpopular, participants across all countries complained that it made the questionnaire hard to read.

'Erm, the second column with the yes or no bit is on the side which makes it a bit harder to read erm so if it was I done no horizontal that would make it easier'

'The biggest problem with the questionnaire is the layout. Writing that runs vertically is very hard to read!'

One person mentioned that it was very tempting to carry on ticking down the page for the first column thus missing the subsequent columns and the interviewers observed participants doing just that – ticking in the first column of each question (to say whether or not they had used a particular modality) and then missing out the additional questions about number of consultations, reasons for use, and satisfaction with use. This too was common across all countries.

One participant in the UK commented that a person with dyslexia might have trouble completing it and one person in Romania considered that a person with limited education might experience difficulties completing it. One person in the UK suggested that it needed to be visually more interesting perhaps with colour and a similar comment was received in Italy.

All countries reported that the respondents did not read the questionnaire properly thereby failing to complete all the required sections. A number of people in the UK and Italy were confused between questions one & two as they were felt to be very similar possibly suggesting that people didn't understand or remember or recognise the distinction between practitioners with and without bio-medical qualifications.

'no, why have, why is it different to that section? Surely it's the same thing is it?'

Question 2 was only to be answered if respondents had reported in Question 1 that they had not seen their physician in the last 12 months however all countries had respondents who continued to answer question 2 when they should not have done so.

In question 3, there are 3 spaces in which to record the names of vitamins and remedies etc. but in all countries except Spain, some respondents did not have enough space to list all the vitamins or remedies they were taking and did not know how to choose which ones to report.

3.2.6 Memory and choosing response options

Respondents in Romania, the UK and the Netherlands found it confusing and difficult to have to recall from a twelve month period whether they had used a modality and then switch to recalling over a 3 month time period reporting how many times they had used it. A number of people from each country couldn't remember how many times they had seen a practitioner at all. One person in the UK summed up this problem by saying it was difficult to remember, people didn't keep account of how many times they'd been to a doctor etc. Another person said that twelve months was a long time to think back over.

'I think with uh, a lot of these questionnaires, they need to know specific numbers of how many times you've been to doctors and things like that, and um, I can't always remember...'

The question of how to complete the questionnaire was of concern to respondents in the UK and Italy for example in question 3, people did not know if they could leave the question blank if they didn't take a supplement or if they had to tick 'no' for each option. In the UK several people commented that they did not know whether to put a cross in each box ('because computer surveys use a cross') or a tick and in Italy 6 people didn't know how to mark their answers i.e. yes/no/tick/cross etc.

In rating the helpfulness of an intervention, in the UK, the Netherlands and Spain respondents felt that the difference between 'somewhat helpful' and 'very helpful' was too large and that an intermediate option should have been available.

3.3 Pilot Study – quantitative data analysis

The focus of this section of the report is on the characteristics of the I-CAM-Q, in particular the extent to which the questionnaires were incorrectly or incompletely filled out. While some information about the measured prevalence of CAM use is reported, prevalence data are only commented on when relevant to our objectives.

3.3.1 Demographic and study sample characteristics of the participants

The demographic results of participants across countries are presented in Table 2.

<u>Table 2</u>: Demographic characteristics of study participants by country

	Total	UK	Romania	Italy	Spain	Netherlands
Number of participants	290	50	50	40	50	50
Age Mean (SD)	43.60	41.32	47.22	37.40	47.2	
	(16.02)	(18.60)	(12.26)	(12.26)	(12.93)	
	Total	UK	Romania	Italy	Spain	Netherlands
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Gender						
Man	64 (34%)	21(42%)	23 (46%)	0 (0%)	20 (40%)	
Woman	126(66%)	29(58%)	27 (54%)	40(100%)	30 (60%)	
Birth Country						
UK	43 (23%)	43(86%)	0 (0%)	0 (0%)	0 (0%)	
Netherlands	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	
Romania	50 (26%)	0 (0%)	50 (100%)	0 (0%)	0 (0%)	
Italy	39 (21%)	0 (0%)	0 (0%)	39 (97.5)	0 (0%)	
Spain	49 (26%)	0 (0%)	0 (0%)	0 (0%)	49 (26%)	
Germany	2 (1%)	1 (2%)	0 (0%)	0 (0%)	1 (25%)	
Other	7 (4%)	6 (12%)	0 (0%)	1 (2.5%)	0 (0%)	
Government funded						
health care						
Yes	183(96%)	44 88%)	50 (100%)	40(100%)	49 (98%)	
Missing	3 (2%)	2 (4%)	0 (0%)	0(0%)	1 (2%)	
Private health insurance						
Yes	32 (17%)	10 20%)	5 (10%)	0(0%)	17 (34%)	
missing	2 (1%)	1(2%)	0(0%)	0(0%)	%)	

Table 3 summarises the sample characteristics by country and shows that whilst most countries recruited some respondents with a lower educational level the samples tended to be from the higher educated groups. Similarly with general health status, each country recruited participants with and without chronic illness but very few self-rated their health status as poor. Most participants self-rated their health as good or very good. In relation to never used, light and heavy CAM users, our samples indicated that each country had participants from all categories.

Table 3: Sample characteristics by country

	Total n (%)	UK n (%)	Romania n (%)	Italy n (%)	Spain n (%)
Highest Education	10tai n (%)	UK II (%)	Romania n (%)	italy n (%)	Spain n (%)
Level					
O level /CSE	11 (6%)	5 (10%)	4 (8%)	0 (0%)	2 (4%)
A level	28 (15%)	5 (10%)	7 (14%)	7 (17.5%)	9 (18%)
Vocational	36 (19%)	7 (14%)	9 (18%)	20 (50%)	0 (0 %)
University	77 (41%)	25 (50%)	13 (26%)	12 (30%)	27 (54%)
Professional	36 (19%)	6 (12%)	17 (34%)	1 (2.5%)	12 (24%)
Missing	2 (1%)	2 (4%)	0 (0%)	0 (0%)	0 (0%)
General Health Status					
Excellent	18 (9%)	9 (18%)	4 (8%)	1 (2.5%)	4 (9%)
Very good	70 (37%)	32 (64%)	18 (36%)	3 (7.5%)	17 (34%)
Good	65 (34%)	8 (16%)	14 (28%)	21 (52.5%)	22 (44%)
Fair	34 (18%)	1 (2%)	14 (28%)	13 (32.5%)	6 (12%)
Poor	3 (2%)	0 (0%)	0 (0%)	2 (5%)	1 (2%)
Chronic Illness					
Yes	59 (31%)	16 (32%)	20 (40%)	14 (35%)	9 (18%)
missing	3 (2%)	2 (4%)	0 (0%)	0 (0%)	1 (2%)
CAM Use					
Non-users	24 (12.6%)	7 (14%)	4 (8%)	9 (22.5%)	4 (8%)
Light users (1-2 modalities)	66 (34.7%)	22 (44%)	8 (16%)	17 (53.5%)	19 (38%)
Heavy users (>2 modalities)	100 (53%)	21 (42%)	38 (76%)	14 (35%)	27 (54%)
(~2 mouanties)	100 (33%)	ZI (4Z/0)	30 (70/0)	14 (33/0)	21 (34/0)

3.3.2 Overview of Missing Data across Questions

The questions which had the most complete data (<10% missing), were the questions that required a Yes or No response (have you seen this provider, have you used this practice, etc.). When CAM modalities were used, for approximately one third of items the respondents failed to report how many times they had used it or their main single reason for using it. The question concerning respondents' perceptions of the helpfulness of each CAM was also skipped one time in ten. Missing data rates broken down by country are reported below. Missing data rates broken down by individual questionnaire item are available in the appendix (Appendix F1–16).

Table 4: Summary of Missing Data across four main I-CAM-Q Questions

		Question	Miss	ing Data
Question Stem	Number	Topic	n	%
Have you used this, yes or no?	1	Provider	67	6%
	2	Physician-delivered	52	7%
	3	Product	26	7%
	4	Self-Care Practice	117	8%
How many times have you used this?	1	Provider	77	30%
	2	Physician-delivered	32	29%
	3	Product	NA	NA
	4	Self-Care Practice	108	50%
Select one reason for using this*	1	Provider	79	31%
	2	Physician-delivered	39	34%
	3	Product	91	34%
	4	Self-Care Practice	62	29%
How helpful was this?	1	Provider	13	5%
	2	Physician-delivered	16	14%
	3	Product	18	8%
	4	Self-Care Practice	23	11%

^{* &#}x27;missing' total includes multiple responses as well as missing responses

Number and % of missing data is calculated as a total across all individual items within each question.

3.3.3 Compliance with Instructions about Question Routing

According to the I-CAM-Q instructions, only respondents who report having seen a physician in the past 12 months (on Question 1) should complete Question 2. On average, two thirds of respondents who said that they had not seen a physician in the past 12 months ignored these instructions and went on to complete Question 2. This is not a problem for the majority of these participants as they completed Question 2 by again ticking 'no'; they had not seen each practitioner. However, it does present an interpretive difficulty for the few

occasions (7 across all items and all countries) when participants went on to report that they had received one or more of the practices listed in Question 2 from a physician, thus contradicting their response in question 1 that they had not seen a physician. All other analyses of Question 2 responses include only those participants who had reported seeing a physician in Question 1.

3.3.4 Missing Data for Prevalence of Use Items

Across all four I-CAM-Q questions, the items that asked respondents whether or not they had used a particular CAM had in total between 6% and 8% missing data. Much of the missing data was from the English and Spanish versions of the I-CAM-Q; there was very little missing data on these questions from the Romanian and Italian versions.

Table 5: Missing data for prevalence of use items by country

		Q1	Q2	Q3	Q4
		Providers	Physician-delivered	Products*	Self-care
Total	Expected n	1140	765	354	1520
	Missing n	67	52	26	117
	Missing %	6%	7%	7%	8%
UK	Expected n	300	165	148	400
	Missing n	9	11	9	36
	Missing %	0.80%	7%	6%	9%
Romania	Expected n	300	225	121	400
	Missing n	0	0	14	0
	Missing %	0	0%	12%	0%
Italy	Expected n	240	165	38	320
	Missing n	0	2	1	0
	Missing %	0	1%	3%	0%
Spain	Expected n	300	210	47	400
	Missing n	58	39	2	81
	Missing %	5%	19%	4%	20%

^{*}Prevalence of use of products over the past 3 months

3.3.5 Missing Data for Frequency of Use Items

Respondents who reported having seen a provider or used a practice were asked how many times they had used the modality in the past 12 months. More than 10% of responses were missing for each country for each of I-CAM-Q Questions 1, 2, and 4. I-CAM-Q Question 3 (about CAM products such as supplements and vitamins) does not ask about frequency of use. On the English version, missing data rates were consistently over 50%. On the Romanian

version, missing data was most common for the self-care practices. On the Italian version, missing data was most common for the physician-provided therapies. On the Spanish version missing data rates were similar and over 30% for each set of modalities.

Table 6: Number and proportion of missing responses for frequency of CAM use by country

		Q1	Q2	Q4
		Providers	Physician-delivered	Self-care
Total	Expected n	255	110	214
	Missing n	77	32	108
	Missing %	30%	29%	50%
UK	Expected n	52	7	49
	Missing n	27	6	32
	Missing %	52%	86%	65%
Romania	Expected n	96	56	69
	Missing n	13	7	35
	Missing %	14%	13%	51%
Italy	Expected n	42	9	31
	Missing n	12	7	5
	Missing %	29%	78%	16%
Spain	Expected n	65	38	65
	Missing n	25	12	36
	Missing %	38%	32%	55%

3.3.6 Missing Data and Compliance with Instructions for Reasons for Use Items

Respondents who reported having seen a provider or used a product or practice were asked to select the single main reason for their use. Some respondents failed to tick any reason while others ticked more than one. Rates of incorrect responses were similar across all 4 I-CAM-Q questions, ranging from 29% to 34%. Among the incorrect responses, it was more common for respondents to select more than one reason for use than to select no reasons for use; this was true overall and for the English, Romanian, and Italian versions. Rates of incorrect responses were substantial for all the different language-versions of the I-CAM-Q, typically above 10% for each question. The Romanian version consistently produced the largest proportion of incorrect responses and respondents had a strong tendency to tick more than one reason for using each provider. The Spanish version produced a small proportion of incorrect responses and incorrect responses were more often due to missing data than selecting multiple reasons for use.

<u>Table 7</u>: Missing and excess reasons for using each modality by country

		C	Q1		(2	C	(3	C	Q 4
				-	ician-		_		
		Prov	riders	deliv	ered	Proc	lucts	Self-	-care
		n	%	n	%	n	%	n	%
Total	Expected	255		116		267		212	
	Missing	24	9%	11	9%	29	11%	32	15%
	>1 reason	55	22%	28	24%	62	23%	30	14%
	Total incorrect	79	31%	39	34%	91	34%	62	29%
UK	Expected	52		9		61		49	
	Missing	2	4%	1	11%	3	5%	5	10%
	>1 reason	5	10%	1	11%	5	8%	2	4%
	Total incorrect	7	13%	2	22%	8	13%	7	14%
Romania	Expected	96		59		121		67	
	Missing	12	13%	9	15%	14	12%	18	27%
	>1 reason	40	42%	23	39%	42	35%	25	37%
	Total incorrect	52	54%	32	54%	56	46%	43	64%
Italy	Expected	42		10		38		31	
	Missing	1	2%	0	0%	2	5%	1	3%
	>1 reason	9	21%	4	40%	14	37%	3	10%
	Total incorrect	10	20%	4	40%	16	42%	4	13%
Spain	Expected	65		38		47		65	
	Missing	9	14%	1	3%	10	21%	8	12%
	>1 reason	1	2%	0	0%	1	2%	0	0%
	Total incorrect	10	15%	1	3%	11	23%	8	12%

3.3.7 Missing Data for Helpfulness Items

Respondents who reported having seen a provider or used a CAM product or self-care practice were asked to rate how helpful they found each CAM modality. A small proportion of respondents did not provide a satisfaction rating. Over the 6 different providers asked about in Question 1, missing data was recorded for 5% of satisfaction ratings. The proportion of missing data was similar across all countries. Over the 5 different physician-provided therapies asked about in Question 2, missing data was recorded for 14% of ratings. There was no missing data on these items from Italy. Over the 12 products in Question 3, missing data was recorded for 8% of ratings. There was no missing data on these items from Italy. Over the 8 self-care practices listed in Question 4, missing data was recorded for 11% of ratings. There was no missing data on these items from Italy.

<u>Table 8</u>: Missing data for helpfulness ratings by country

		Q1	Q2	Q3	Q4
			Physician-		
		Providers	delivered	Products	Self-care
Total	Expected n	257	113	235	214
	Missing n	13	16	18	23
	Missing %	5%	14%	8%	11%
UK	Expected n	53	7	52	50
	Missing n	3	1	5	3
	Missing %	6%	14%	10%	6%
Romania	Expected n	96	58	113	68
	Missing n	5	13	12	15
	Missing %	5%	22%	11%	22%
Italy	Expected n	42	9	31	31
	Missing n	2	0	0	0
	Missing %	5%	0%	0%	0%
Spain	Expected n	66	39	39	65
	Missing n	3	2	1	5
	Missing %	5%	5%	3%	8%

3.3.8 Web-Based Delivery: The Dutch Pilot

The Dutch respondents included 4 people (8%) who had not used CAM in the last 12 months, 22 (44%) who were light users (1-2 modalities) and 24 (48%) who were heavy users. Other demographic and clinical characteristics were not collected.

As expected, the web-based version generally had lower levels of missing data than the paper-based versions of the I-CAM-Q (see Table 9). That there was any missing data at all demonstrates that even web-based delivery mechanisms can be subject to error or misuse.

<u>Table 9</u>: Summary of Missing Data across Four Main ICAMQ Questions for the Web-Based Pilot (Dutch version of the I-CAM-Q)

		Question	Expected	Miss	ing Data
Question Stem	Number	Topic	n	n	%
Have you used	1	Provider	50	0	0
this, yes or no?	2	Physician-delivered	50	0	0
	3	Product	50	0	0
	4	Self-Care Practice	50	0	0
How many times	1	Provider	56	6	11%
have you used	2	Physician-delivered	14	1	7%
this?	3	Product	NA	NA	NA
	4	Self-Care Practice	23	2	9%
Select one reason	1	Provider	56	6	11%
for using this	2	Physician-delivered	14	1	7%
	3	Product	86	0	0
	4	Self-Care Practice	23	2	9%
How helpful was	1	Provider	56	6	11%
this?	2	Physician-delivered	14	1	7%
	3	duct	86	20	23%
	4	Self-Care Practice	23	2	9%

4. Discussion

4.1 Summary

The results of our study indicate that the I-CAM-Q has low face validity and acceptability to respondents in 5 EU countries. Problems associated with the layout, the terminology and the response options were detected through cognitive interviews. Quantitative analysis demonstrated substantial missing data or incorrect answers which largely confirmed our qualitative findings. We suggest that the I-CAM-Q requires considerable further development work if it is to be used in future studies of CAM prevalence across the EU and associated states.

4.2 Translations

There is wide variation and popularity of different CAM modalities across EU countries. The terms on the questionnaire that were unknown in some countries or likely to be misunderstood were translated to a term that would be more easily understood without much difficulty for example *herbal medicine* translated into Spanish as *medicinal plants*. In some countries however, there were more challenges for example there were cultural objections to including the term *Spiritual Healing* as a CAM therapy due to it being under the jurisdiction of the Church. The issue was resolved by individual countries including an explanation of the 'CAM use' of the term where necessary. It was agreed that for the EU, it may be necessary to have some clear definitions of church based healing practices and those that occur outside churches in relation to this term for future studies.

There was considerable debate about which healthcare providers are legally allowed to provide CAM therapies in each country. In Germany for example the only two registered health care disciplines are physicians or 'Heilpraktiker' although the group were aware that spiritual healing for example was available outside the remit of normal medical care. In Italy only medical doctors may provide certain types of CAM. It was emphasised that the I-CAM-Q was designed to ask fundamental questions about who provided what kinds of treatments and that these needed to be consistent with the local population. Consequently it was accepted that in the future, question 1 and question 2 may need modifying, dependent on prevailing national legal systems and the delivery of healthcare within each country. For example, in the German situation the question might simply ask whether the respondent was seeing a medically qualified person or a 'Heilpraktiker' and then asked for each of them which therapy they might be providing.

4.3 Pilot study

4.3.1 Demographic of the participants

We broadly achieved our aims of including participants with a range of health, education and different experiences of CAM however a high proportion of respondents across countries reported good or very good self-rated health status and higher levels of education. It is probable therefore, that we may not have identified problems in the questionnaire that would be experienced only by people with lower health literacy and in poor health. Whilst we recruited participants across a range of CAM experience the majority were light or heavy users of CAM with only a few being non users. This was probably due to the locations in which countries recruited for participants, but might also reflect a difficulty recruiting non-CAM-users to complete a survey that focuses on CAM use. The questionnaire itself would be difficult to use to identify the CAM prevalence because Readers should be aware that we presented figures on CAM use in table 3 only to provide an approximate check on whether we had achieved our recruitment aim of including people with a variety of CAM experiences and our figures should *not* be used as an estimate of CAM prevalence in the EU because firstly, we did not aim to recruit a representative sample of the population and secondly, the validity of the I-CAM-Q is yet to be established.

4.3.2 Data analysis

Terminology: names of health care practices and practitioners

There were frequent problems across all countries relating to the names of practitioners and practices with many people not knowing the meaning of the terms (and so proceeding to leave responses blank). This was true of people who both had and had not used a particular practice, suggesting that treating missing data as negative responses is an unsafe assumption and instead it would be better to modify or explain problematic terminology for respondents.

The term *physician* was not understood well in the UK. Respondents mentioned that they felt it was an American word and indeed the I-CAM-Q whilst developed by participants from several countries was led by the USA where the term is in common use [15]. This highlights the fact that across English speaking countries there are differences in language and therefore translation from the word *physician* to *doctor* for UK participants would have been helpful. Other EU countries did not have the same problem with this word because they had already translated all the terms to make them more suitable for their local populations.

Despite homeopathy and herbal medicine being arguably two of the most prevalent CAM's, these terms were not known across countries or respondents didn't know the difference between them. Acupuncture, again a prevalent CAM utilised by both medically qualified and lay practitioners was not well understood. One person recruited from a chiropractic clinic in the UK didn't understand the term which suggests that the public are generally unaware of the formal terminology for CAM. Some simple explanations of terms could have aided participants to complete the questionnaire more accurately.

Across all countries the self-help techniques highlighted in question 4 caused much confusion as people didn't know what they were and in general respondents thought that self-help techniques were preventative measures rather than interventions and therefore they were unable to rate how helpful they had been. This was also true for question 3 which asked about the use of vitamins and natural remedies. If large sectors of the population see self-help techniques as preventative measures then the wording of question 4 is currently not measuring the construct as it is understood by populations. The qualitative data demonstrated considerable missing responses for the 'helpfulness' ratings of more than 10% across countries which may be in part because people were simply unable to answer the question. For those that did, there is a potential for their answers to be guesses meaning that the accuracy of the data is limited.

A further weakness we identified was that if a person didn't use CAM or hadn't been to a healthcare provider in the last 12 months then there was little for them to complete. If people do not feel that a questionnaire is relevant or of interest to them, then they are less likely to fill it in at all [17] which in this case could result in biased estimates of CAM use within the populations surveyed with the current I-CAM-Q.

<u>Understanding categories</u>

Respondents didn't understand some of the categories and suggested they may be too broad and open to interpretation. Even the category complementary medicine was misunderstood in several countries with respondents now knowing whether a therapy they had used was CAM or not again reflecting that the public are not familiar with CAM terminology. A number of the self-help techniques were thought to be synonymous and therefore people couldn't distinguish between them. A definition of a self-help technique used as an intervention and separately as a preventative may have helped participants understand how to complete the questions.

One of the challenges with choosing a category is that people may not understand if their CAM practitioner is also medically qualified as some medical practitioners also practice CAM. This is an issue when answering questions 1 and 2 because question 2 relies on people answering it only if they have not seen their doctor. If the respondent doesn't appreciate that their CAM practitioner is a doctor then they may complete question 2 when they

shouldn't or complete question 1 incorrectly. Considering that on average two thirds of respondents completed question 2 when they shouldn't, as well as not reading the questionnaire properly, this needs to be addressed.

Many non-medical registered CAM practitioners are multi skilled meaning that they may offer homeopathy and be consulted in that vein but then give a different treatment such as acupuncture and then it is not easy for a respondent to decide how to categorise the treatment they had. For example, in the Netherlands some respondents mentioned that 'some CAM physicians are known as a specific therapist but they also practice other kinds of therapies' and one respondent said they were treated by a herbalist but received massage and relaxation techniques. It was therefore difficult for them to answer the questions and is an area where some simple instructions or clarifications for the participants may have helped them to answer more accurately.

Reasons for use

There were large amounts of incorrect responses and missing data across all countries for this section of each question. Respondents have the option to give 1 main reason for consulting a practitioner however some people failed to respond and others ticked more than 1 reason. Overall approximately 30% of respondents across countries answered incorrectly to this section of all 4 questions, more than 10% in each country and there are some suggested reasons for this. As previously discussed, interviewers from all countries reported that respondents were not reading the questionnaire properly and therefore not completing all the sections. Secondly, it is quite possible that people consult a practitioner for more than one reason and they cannot choose between reasons hence they simply ticked more than one option. Indeed, it has been reported that people sometimes use CAM for multiple reasons that go beyond any single biomedical diagnosed health condition [18-21]. Requiring people to select a single reason for use is therefore likely to lead to an inaccurate understanding of CAM use.

There was also great confusion across countries in relation to the definition of a chronic or acute illness both in length of time to constitute one or the other or type of ill health. Some participants were not even sure of the definition of the word illness. This suggests that the general public are not properly cognisant with the medical definition of an acute or chronic illness and some other method of measuring illness (and a definition of what constitutes illness) would be more appropriate and enable participants to answer the questions adequately.

Other options

Participants in the UK were generally confused by the 'other' options at the bottom of each question. They were not sure what the 'options' or 'other' were for indeed one person put

the name of their medical drug. In fact the options were for therapies people had used but which were not on the list.

Layout

Respondents from all countries, even though they were drawn from well-educated strata of the population, found the questionnaire hard to read and understand. Of particular significance and the recipient of some of the strongest comments was the use of vertically alignment for some of the response options. Other comments ranged from having too much information on the page, being unclear, needing extra instructions and lacking in colour or visual interest. This suggests that the acceptability of the I-CAM-Q to the study population is poor. As previously discussed, many participants across countries missed answering some or the response options e.g. frequency of visits or reasons for use because they didn't see them or because of the temptation to tick rows in a descending order and therefore simply miss them out and this resulted in a substantial amount of missing data as demonstrated in the quantitative analysis. At least 10% of data was missing for the *reasons for use* and *frequency of visit response* options across countries.

In some countries where definitions of certain terms had been added to help participants understand what they were, the question then ran over 2 pages and participants felt it added to the confusion. Unfortunately in these instances keeping each question to one side of paper would have meant having to use a very small font, a complaint received in one of the countries so neither option was received positively.

Whilst problems of missing data and of incorrect responses may not be an issue for a telephone/face-to-face or internet questionnaire (where responses can be required by the person administering the survey or the online questionnaire programme) they are of significant concern as a self-administered tool if participants find a questionnaire difficult to read and clearly it leaves the questionnaire open to inaccuracy and bias.

Memory and choosing response options

During interview, respondents frequently reported that they couldn't remember how many times they had seen a practitioner and some of them simply said they were guessing meaning that overall the data could have been subject to recall bias. Others may have guessed but not mentioned it. Respondents felt that recall over a 12 month period was too long and therefore difficult and also to attempt to recall over two different times periods as asked in the questionnaire, was confusing. Our quantitative data on *frequency of visit* for Question 1, demonstrated that overall there was 30% missing data with more than 10% missing for each country, 29% missing data for question 2 with more than 10% missing for each country and 50% missing data for question 4 with more than 50% missing data for each country. This is a substantial limitation of the questionnaire and further development would

be necessary to present response options that respondents found acceptable and which minimise recall bias. Opinion varies as to the appropriate timescale for questions such as these and the optimal timescale might differ for different CAM practices. For example, infrequent and salient events (e.g. some visits to practitioners) can be recalled accurately by counting over longer periods, but the frequency of high frequency or low salience events (e.g. some self-care practices) is more likely to be estimated over longer periods based on recall of recent occurrences [22].

In rating the helpfulness of a therapy some respondents across countries who properly read the questions complained that there needed to be a category between **somewhat helpful** and **very helpful** because the gap between them was currently too large. A Likert scale of helpfulness comprising more points could help participants choose a more appropriate response although the issue of rating a therapy used as a preventative still remains. One solution would be to remove questions about helpfulness altogether and leave such issues for efficacy and effectiveness studies rather than for prevalence surveys. We do not recommend doing this as an indication of perceived helpfulness of therapies across a population could be useful for certain purposes.

4.3.3 Strengths and limitations (of our pilot)

We translated the questionnaire into more than the 3 EU languages than we had originally aimed to provide and each translated version retained the questionnaire format and essence of each listed therapy according to individual country variations. We achieved our research aims in recruiting members of the population across countries from all the health, education and CAM use categories we required and recruited the sample size deemed necessary to assess the face validity, acceptability and scores of each different language version of the I-CAM-Q. We identified a number of problematic items, response items and layout difficulties in the questionnaire and these findings were comparable across countries.

The data is limited in that we did not recruit many participants with poor self-rated health and lower health literacy and therefore we may not have discovered problematic issues in the questionnaire for these sectors of the population. We only piloted the questionnaire in 5 EU countries although we suspect that respondents in other Countries would have given us similar data, given the relative consistency of results across the countries that were included. As with any self-report study, it is possible that participants in the cognitive interviews did not speak aloud all of their relevant thoughts when completing the I-CAM-Q or did not voice misunderstandings during the subsequent probing interview. This could mean that there are other problems with the I-CAM-Q that we have not identified.

4.3.4 Recommendations

The following recommendations are derived from the insights provided by the translation process, the qualitative data and the quantitative data. Before the I-CAM-Q can be used as a self-report measure to survey CAM use in the European population, we recommend the following modifications:

- 1. Revise the layout so that all the writing reads horizontally.
- 2. Make sure that the questionnaire uses terms and definitions that are relevant to the country in which it will be administered. Do not assume that English is a universal language and make sure that UK, Canadian, US and for instance Australian versions of the questionnaire are adequately piloted in that country before use.
- 3. Make the questionnaire accessible to non CAM users, if we wish to evaluate the presence of CAM, by including questions about conventional medicine.
- 4. Do not systematically separate out physician-delivered from other forms of practitioner-based CAM. Instead, present a single list of all core practitioner-based CAM modalities. This recommendation is based on the observations that people did not reliably distinguish between the current questions 1 and 2 (i.e. between physician and non-physician-delivered therapies) and did not follow the question routing regarding question 2.
- 5. Revise the 'frequency of use' items. These items should either be removed, the recall period should be reduced, or fixed options should be provided (e.g. daily, weekly, monthly).
- 6. Allow participants to select more than one reason for use or remove this item from the questionnaire. If retaining the reasons for use question, then the response options 'acute illness' and 'chronic illness' need to be revised/defined.
- 7. Remove questions about helpfulness or change the response scale to allow more nuanced responses while retaining a 'not sure' option.
- 8. Remove some of the lesser-known modalities (e.g. Qi Gong) and define others (e.g. Spiritual Healing).
- 9. Remove the distinction in question 3 between different types of CAM products. Instead, define the range of CAM products of interest and allow participants to list up to 12, without having to categorise them as homeopathic remedies, herbs, vitamins/minerals, or other supplements. Include a single tick box for participants to report that they do not use any CAM products. This recommendation is based on the observations that (a) many participants did not know which category their products belonged to and (b) if participants used more than 3 products from any one category they felt forced to select just 3 to report (even if they used none from the other categories).
- 10. In the instructions, add a definition of CAM and an explanation that participants should use the 'other' options to name additional CAM modalities that they have used.

11. Increase the acceptability and face validity of the questionnaire for non-CAM-users. This could be achieved by adding items about the use of conventional health services or by more clearly sign-posting a route through the questionnaire for non-users.

4.4 Conclusions

Whilst we met our aims in recruiting across a range of education, health and CAM use categories our samples generally came from healthy, well-educated sectors of the population. Despite this, our qualitative analysis demonstrated that many participants found that the layout of the questionnaire made it difficult to read meaning they skipped or did not 'see' a number of sections which they should have completed or completed sections that they shouldn't. Furthermore, they didn't understand many of the terms thus finding it problematic to answer the questions properly. The quantitative data analysis confirmed our findings in that we had substantial missing data and incorrect responses in sections of the questionnaire relating to frequency of visits, reasons for use and helpfulness of a health care or self-help practice. Our data suggests that the I-CAM-Q has low face validity and acceptability in English speaking EU countries and translated EU versions, casting doubt on the accuracy of any data collected using it. This leads us to conclude that the I-CAM-Q requires substantial further work to make it a useful instrument for measuring CAM use across the EU.

References

- [1] Eisenberg DM, Davis RB, Ettner SL, Appel S, Wilkey S, van Rompay M, et al. Trends in alternative medicine use in the United States 1990-1997- Results of a followup national survey. JAMA 1998;280:1569-75.
- [2] Fox P, Coughlan B, Butler M, Kelleher C. Complementary alternative medicine (CAM) use in Ireland: A secondary analysis of SLAN data. COMPLEMENT THER MED 2010.
- [3] Hartel U, Volger E. Inanspruchnahme und Akzeptanz klassischer Naturheilverfahren und alternativer Heilmethoden in Deutschland Ergebnisse einer reprasentativen Bevolkerungsstudie. Forschende Komplementarmedicin Klass Naturkeilkd 2004;11:327334.
- [4] Hunt KJ, Coelho F, Wider B, Perry R, Hung SK, Terry R, et al. Complementary and alternative medicine use in England: results from a national survey. Int J Clin Pract 2010;64(11):1496-502.
- [5] Molassiotis A, Fernandez-Ortega P, Pud D, Ozden G, Scott JA, Panteli V. Use of complementary and alternative medicine in cancer patients: a European survey. Ann Oncol 2005;16(655):663.
- [6] Bodeker G, Ong CK, Grundy CBC, Shein K. WHO Global Atlas of Traditional Complementary and Alternative Medicine. WHO. Kobe; 2005.
- [7] Quandt SA, Verheor MJ, Arcury TA, Lewith GT, Steinsbekk A, Kristoffersen AE, et al. Development of an international questionnaire to measure use of complementary and alternative medicine (I-CAM-Q). J Altern Complement Med 2009;15(4):331-9.
- [8] Jay EM, Thorn B. Spiritual/Religious Values and Attitudes Regarding Complementary and Alternative Medicine. The University of Alabama NcNair Journal 2009.
- [9] Bains SS, Egerde LG. Association of Health Literacy with Complementary and Alternative Medicine Use: A Cross-Sectional Study in Adult Primary Care Patients. BMC Complementary and Alternative Medicine 2011;11(138).
- [10] Quandt SA, WP4 Team. Minutes of the ICAMQ teleconference. 2011.
- [11] Guethlin C, WP4 Team. WP4 ICAMQ teleconference. 2011.
- [12] Quandt SA. Comparing 2 questionnaires for comparing CAM use in a multi ethnic population of older adults. 2011.
- [13] Hegyi G. Hungarian Military Use of Acupuncture and other Complementary and Alternative Medicine (CAM). 2012.
- [14] Cull A, Sprangers M, Bjordal K, Aaronson N, West K, Bottomley A. EORTC Quality of Life Group Translation Procedure. Second Edition edn. EORTC, Brussls; 2002.
- [15] Quandt SA. person email. 2011.
- [16] Quandt SA, Fonnebo V. General principal on adapting the I-CAM-Q. 2011.

- [17] Edwards P, Roberts I, Clarke.M., DiGuiseppi C, Pratap S, Wentz R, et al. Increasing response rates to postal questionnaires: systematic review. British Medical Journal 2002;324:1183-93.
- [18] Astin JA. Why patients use alternative medicine. Results of a national study. Journal of the American Medical Association 1998;279:1548-53.
- [19] Bishop FL, Lewith GT. Who uses CAM? A narrative review of demographic characteristics and health factors associated with CAM use. Evidence-based Complementary and Alternative Medicine 2010;7:11-28.
- [20] Sirois FM. Motivations for consulting complementary and alternative medicine practitioners: a comparison of consumers from 1997-8 and 2005. BMC Complementary and Alternative Medicine 2008;29:8-16.
- [21] Verhoef MJ, Balneaves LG, Boon HS, Vroegindewey A. Reasons for and characteristics associated with complementary and alternative medicine use amoung adult cancer patients: A systematic review. Intergative Cancer Therapies 2005;4:274-86.
- [22] Bradburn NM, Sudman S, Wansink B. The Definitive Guide to Questionnaire Design For Market Research, Political Polls and Social and Health Questionnaires, Revised Edition. San Francisco: Jossey Bass; 2004.

<u>Appendix</u>

Appendix A	. Ethical Approval documents					
A1 UK		43				
A2 Italy		44				
A3 Spain		46				
A4 Romania		48				
Appendix B	. I-CAM-Q and translated versions. Instructions and demographic data					
B1 UK		49				
B2 Italy		53				
B3 Spain		57				
B4 Romania		61				
B5 Netherlar	nds	65				
B6 Hungary		70				
B7 Instructio	ns for completion	74				
B8 Demogra	phic questions	75				
A2 Italy A3 Spain A4 AR Romania A4 AR Romania Appendix B. I-CAM-Q and translated versions. Instructions and demographic data B1 UK B2 Italy B3 Spain B4 Romania B6 Hungary B7 Instructions for completion B8 Demographic questions B7 Instructions for completion B8 Demographic questions B7 Instructions for complete information pack B9 Instructions for complete information pack B1 Invitation to participate B2 Cognitive interview pack B1 Invitation to participate B2 Cognitive interview summaries B1 UK B2 Italy B3 Spain B4 Romania B5 Netherlands B6 Hungary B7 Instructions for complete information pack B1 Invitation to participate B2 Cognitive interview summaries B1 UK B2 Italy B3 Spain B4 Romania B5 Netherlands B6 Hongary B7 Instructions for complete information pack B8 Italy B9 Instruction to participate B9 Italy B9 I						
Appendix D	. Cognitive interview pack					
D1 invitation	to participate	77				
D2 consent form						
D3 Interview	topics	79				
Appendix E	. Cognitive interview summaries					
E1 UK		80				
E2 Italy		84				
E3 Spain		86				
E4 Romania		88				
E5 Netherlan	ods	90				
Appendix F	. Tables of missing data rates broken down by individual questionnaire it	em				
Table F1.	Missing data and use of providers in the last 12 months	94				
Table F2.	Missing data and use of physician-delivered CAM in past 12 months	94				
Table F3.	Responses to Q2 by participants who had reported not seeing a physician	95				
Table F4.	Missing Data and Current Use of Herbal, Vitamin, Homeopathic,					
	and Supplement Products	96				
Table F5.	Missing data on use of self-care practices in the last 12 months	97				
Table F6.	Number and proportion of missing responses for frequency of provider visits	98				
Table F7.	· · · · · · · · · · · · · · · · · · ·					
	···	98				
Table F8.		99				
Table F9.	Missing and excess reasons for using each provider	100				
Table F10.	Missing and excess reasons for using each therapy	101				

CAMbrella Work Package 4 Report Part II

Page	42
гадс	44

Table F11.	Missing and excess reasons for using each product	102
Table F12.	Reasons for using each self-care practice	104
Table F13.	Missing data and helpfulness ratings for each provider	106
Table F14.	Missing data and helpfulness ratings for each therapy	107
Table F15.	Missing data and helpfulness ratings for each product	108
Table F16.	Missing data and helpfulness ratings for each self-care practice	110

Appendix A. Ethical approval documents

A1. UK



Ref: Eardley 130511

Dr Susan Eardley CIMRU, Primary Medical Care Aldermoor Health Centre Aldermoor Close Southampton SO16 55T

1st June 2011

Ethics Approval Number: SOMSEC093.10

Dear Dr Eardley

Re: A Pilot Study of an International Questionnaire to Measure the use of Complementary and Alternative Medicine (I- CAM- Q) in the EU and associated states

Thank you for submitting your amended documentation which addressed the Committee's issues relating to the above project I am pleased to inform you that full approval was granted for the study application form dated 27th May 2011 (version 2), the participant information sheet dated 27th May 2011 (version 2), the consent form dated 27th May 2011 (version 2), the advertisement dated 27th May 2011 (version 2) and the interview guide dated 27" May 2011 (version 2). Approval is valid from 1st June 2011 until 31" December 2011, which is the end date specified in your application. We will be in touch with you again at this time to confirm that your project has been completed.

Please note the following points:

- In order to adhere to University Policy, you must have received notification of University Insurance cover
- before you commence your study.

 The above ethics approval number must be quoted in all correspondence relating to your research, including emails
- If you wish to make any substantive changes to your project you must inform the School of Medicine Ethics Committee as soon as possible.

We wish you well with your research.

Yours sincerely

Dr John Holloway

Chair: School of Medicine Ethics Committee

Dr Martina Prude, Legal Services, University of Southampton

Please reply to: Ms Helen Flynn School of Medicine Ethics Committee School of Medicine, Schrift in pron General Hospital, Mallpolia Sou, South Academic Block, Tremora Rossi, Southampton 50:16 SYD United Kingdom

University of Southsimpton, Highfield Campus, Southampton 9017 tRJ United Kingdom Tel: +44 (0123 8059 5000 | Fax: -44 (0)23 8059 5131 | www.southamptom.co.uk

A2. Italy

ao_re Protocollo n. 2011/0029875 del 07/11/2011 Pagina 1 di 5



Arcsopedalo S. Mana Nuova

istituto in tecnologio avanzate e model i assistenziali in oncologia i-Bluis di Kicovice e Cura a Carattere Scientifico



COMITATO ETICO PROVINCIALE

RE, Prot. c.

Dott Francesco CARDINI ASSR Male Aldo Moro (21) BOLOGNA

Prof. Glovanni Haffista La SALA Direttore S.C. di Ostetricia e Ginecologia Azienda Ospedaliera Arcispedale Santa Mana Nuova SLDE

Dott.ssa Maria Caternia CITRO Medico a contratto SiC, di Ostetnicia e Ginecologia Azlonda Ospedol era Arcispedale Santa Maria Nuova SEDE

Doff Eurgi RIZZO Direttore Viedico Ospedaliero F.F Azienda Ospedalera Aroispedale Santa Maria Nilova SEDE

Oggetto:Studio esservazionale indipendente: "Studio pilota di un questionario internazionale per la valutazione dell'uso di medicine alternative è complementari (I-CAM-Q) in Europa e negli stati associati" proposto dall'Università di Southampton – CIMRU – Primary Medical Care - Aldermoor Health Centre – Aldermoor Close e coordinato in Italia dall'A.S.S.R. – Agenzia Sanitaria e Sociale Regionale - Emilia-Romagna (Dott. Francesco Cardini) presso la S.C. di Ostetnicia e Ginecologia.

Allegati: n. 2

Si comunica che il Comitato Etico Provinciare nelle seduta del 17 10 2011 ha esaminato lo studio per il quale ha espresso <u>parera positivo</u>.

ao re Protocollo n. 2011/0030631 del 14/11/2011 Pagina 1 di 2

SERVIZIO SANITARIO REGIONALE
EMILIA ROMAGNA
Azienda Ospedaliera di Reggle Emilia

istituto in tecnologia avanzate e modelli assistenziali in cocologia legituro di Ricavero e Cora a Carattere Scientifico

Andispedate 5, Maria Nuova Olregione Sports na Consider Medica Depedationa

Roggio Emilia, 1

Datt. Luig- Rigze - Carefreis F.f.

Prof. o.

Dot Francesco CARDINI ASSR Viale Aldo Maro | 21 BOLOGNA

Prof. Giovarin: Ballista La SALA Direttore S.C. di Ostetricia e Ginecologia Azienda Ospedalis/a Arcispedale Santa Maria Nuova SEDF

Dott ssa Maria Caterino CITRO Medice a contrarto S.C. di Ostetricia e Ginecologia. Azienda Öspecaliera Arbispedalo Santa Maria Nuova SEDÉ

Ufficio Farmaceutico Ospedale "L. Spallanzani" Viale Umborto I", 50 42100 REGGIO HMILIA

Quoetto: Studio osservazionale Indipendente: "Studio pilota di un questionario internazionale per la valutazione dell'uso di medicine alternative e complementari (I-CAM-Q) in Europa e negli stati associati" proposto dall'Università di associati" proposto dali'Università di Southampton - CIMRU – Primary Medical Care -Aldermoor Health Centre - Aldermoor Close e coordinato in Italia dall'A.S.S.R. - Agenzia Sanitaria e Sociele Regionale - Emilla-Romagna (Dott. Francesco Cardini) presso la S.C. di Catetricia e Ginecologia.

Richiamata e confermata la disposizione n. 921 del 17 07.2008 di celega (male, ai sensi Richiamata e confermata la disposizione n. 921 del 17 07.2008 di celega tingle, ai sensi dell'art. 3 del D.M. 21.12.2.007, al GE provinciale della valutazione del a documentazione di oui all'allegato 1 del D.M. 21.12.2007, da parte del Dott. Giorgio Mazzi, già Direttore Mascico di Presidio, in qualità di Autorità compotente di questa A.O., ai sensi dell'art. 2 comma 1, lettera t), numico 1 de Di.Lga voin. 211/2003 e a cobiautazzato el sensi dell'Atto Aziendele rivisto e aggiornato, adottato il 18 12.2008, con atto deliberativo ni 36, figura ora ricoperta cal sottoscritto nel ruolo di Direttore Macico Ospedarlero F.F., si comunica che con disposizione nº 1387 del 09.11.2011 del Direttore Medico Ospedarlero F.F. di questa Azienda Ospedallera (autorizzato il effettuazione dello studio di cui all'oggetto, previo rilascio, nella secuta del 17 10 20 11, da parte del Comitato Etizo Previocale, del parera la sua effettuazione, con asservazioni anche sul Front Informativo (A) a (B) ordotti, come da Tayorevole alla sua effettuazione, con osservezioni anche sui Fogil Informativi (A) a (B) prodotti, come da nota prot. n. 29875 del 07.11.2019, trasmessa separatamento da CE provinciale.

Hinesonia Mullica Ospidellere Volto Richgerenso i Alektri Briggia Rimica I egopoto i Archini Filescossi 1997/1997 Norman (Res 001) I. K<u>aros Poto</u>to i

sedy logale (John Riam), comp. 77 - 42100 (regyddinariae | Lauf Rob 2001 | 1 - - 36 ganth America | Banta Bot | 1 - 1 - 4 1008 c

A3. Spain





ACUERDO QUE SE EMITE CON RELACION AL PROYECTO DE INVESTIGACION

A Pilot Study of an International Questionnaire to Measure the use of
Complementary and Alternative Medicine (I-CAM-Q) in the EU and associated

Protocolo: 2011/06 Promotor: Dr Jorge Vas

Titulo: A Plict Study of an International Questionnaire to Measure the use of Complementary and

Alternative Medicine (I-CAM-Q) in the EU and associated states

Accerdo: Informe Favorable

Sevilla, 3 de julio de 2011 El Secretario del Comité Local de Ética e Investigación del Distrito Sanitario Sevilla-Sur

Fdo Rand Volages Rodriguez





RAFAEL VELASCO RODRIGUEZ, COMO SECRETARIO DEL COMITÉ LOCAL DE ETICA E INVESTIGACION, DEL DISTRITO SANITARIO SEVILLA-SUR

CERTIFICA

Que este Comité ha evaluado la propuesta del Dr. Jorge Vas, para realizar el Proyecto Piloto de Investigación a instancias del proyecto CAMbrella, titulado:

A Pilot Study of an International Questionnaire to Measure the use of Complementary and Alternative Medicine (I-CAM-Q) in the EU and associated states

Y considera que:

Se cumplen los requisitos necesarios de idoneidad del protocolo en relación con los objetivos del estudio y estan justificados los riesgos y molestas previsibles para el sujeto, teniendo en cuenta los beneficios esperados.

El procedimiento para obtener el consentimiento informado y el plan de reclutamiento de sujetos previstos son adecuados, así como las compensaciones previstas para los sujetos por por daños que pudieran derivarse de su participación en el estudio.

La capacidad del investigador y sus colaboradores y las instalaciones y medios disponibles son apropiados para llevar a cabo el estudio.

Por tanto, este Comité Local, acuerda emitir informe favorable para dicho que proyecto de investigación sea realizado.

Lo que firmo en Sevilla, a 3 de junto de dos mil once

A4. Romania



P-ta Eftimie Murgu nr. 2, cod 300041, Timișoara, Romania COMISIA DE ETICĂ A CERCETĂRII ŞTIINŢIFICE Tel-fax: +40 256 466001



Nr. 04/10.06.2011

Aviz CECS al UMFTVB

privind validarea unui Chestionar Internaţional pentru măsurarea utilizării Medicinei Complementare şi Alternative (I-CAM-Q), în cadrul proiectului FP7 intitulat CAMbrella (acordul de finanţare nr 241951). CAMbrella este o reţea pan-europeana de cercetare pentru medicina complementară şi alternativă (CAM), la care participă 16 instituţii partenere din 12 ţări europene, inclusiv UMF Timişoara. Membrii CAMBrella (o reţea de cercetare finanţată de UE) din WP4 au tradus I-CAM-Q din limba engleză în următoarele limbi: maghiară, italiană, spaniolă, română şi olandeză.

Comisia de etică a cercetării a fost sesizată de Conf. Dr. Sorin Ursoniu de la disciplina de parazitologie a UMFVB Timișoara și nu se află în conflict de interese cu solicitanții avizului.

Obiectivele studiului sunt: 1. Identificarea oricăror itemi problematici aparţinând I-CAM-Q (de exemplu, itemi care sunt susceptibili de a fi interpretaţi greşit de către respondenţi care au folosit sau nu au folosit CAM); 2. Identificarea oricăror opţiuni de răspuns problematice aparţinând I-CAM-Q, 3. Identificarea oricăror probleme legate de aspectul I-CAM-Q din punctul de vedere al respondenţilor; 4. Identificarea acceptabilităţii I-CAM-Q.

Studiul pilot aplică un chestionar în două metode: un test pilot de auto-completare a versiunii I-CAM-Q, şi 2) interviuri cognitive despre I-CAM-Q. Fiecare centru de cercetare participant va recruta 50 respondenţi pentru a completa I-CAM-Q. Criteriile de includere sunt: adulţi (cu vârsta de 16 ani şi peste), capabili să îşi dea consimţământul informat. Se va realiza un eşantion de convenienţă format din voluntari recrutaţi astfel încât să includă adulţi având fiecare caracteristici definite. Fiecare centru de cercetare va recruta 40 respondenţi care vor completa chestionarul singuri şi îl vor returna prin poştă/internet. Procedura de colectare a datelor în acest braţ al studiului este prospectivă. Fiecare centru de cercetare va recruta, de asemenea, 10 respondenţi care vor completa chestionarul în prezenţa cercetătorului.

Cercetătorii precizează scopul şi obiectivele studiului, asigură asupra confidențialității datelor, fac precizări legate de durata de timp necesară aplicării chestionarului.

Concluzii

CECS a UMFVBT conchide în urma analizei documentației depuse, că sunt îndeplinite criteriile eticii cercetării medicale pe subiecți umani.

Președinte

Prof. dr. Alexandra Enache Medic primar legistera Licential string residue cod 290051

Appendix B. The I-CAM-Q survey

<u>B1. UK</u>

Health Practices Survey

1. Visiting health care providers: Health problems may be attended to by a variety of complementary and conventional health care providers.

		u saw last 3	Please indic	Please indicate the <u>main</u> reason you <u>last</u> saw the provider (Check only <i>one</i>).						
Have you seen any of the following providers in the last 12 months?	Yes No	Number of times you saw this provider in the last 3 months?	For an acute illness/condition, one that lasted less than one month	To treat a long-term health condition (one that lasted more than one month) or its symptoms	To improve well-being	Other (Please specify the other reason)	Very Somewhat Not at all Don't know			
Physician										
Chiropractor										
Homeopath										
Acupuncturist										
Herbalist										
Spiritual healer										
Specified option:										
Other (please specify):										
Other (please specify):										

2. Complementary treatments received from physicians (MDs)

If you have not seen a physician in the past 12 months, please go to question 3.

Some physicians provide complementary, as well as conventional treatments

Have you received	ou nent in	Please indicate	Please indicate the <u>main</u> reason you <u>last</u> received this treatment (Check only <i>one</i>).						
any of the following complementary treatments from a physician in the last 12 months?	Yes No Number of times you received this treatment in the last 3 months?	For an acute illness/condition, one that lasted less than one month	To treat a long-term health condition (one that lasted more than one month) or its symptoms	To improve well-being	Other (Please specify the other reason)	Very Somewhat Not at all Oon't know			
Manipulation]		
Homeopathy]		
Acupuncture]		
Herbs									
Spiritual healing									
Specified option:]		
Other (please specify):]		

3. Use of Herbal Medicine and Dietary Supplements, including tablets, capsules and liquids.

	ently duct?	Please indica	ite the <u>main</u> reas (Check	son that applionly <i>one</i>).	ies to your <i>last</i> use	How helpful did you find this product? (Check only one)		
For each category below, please list up to three products you have used in the last 12 months.	Yes Do you <u>currently</u> use this product? No	For an acute illness/condition, one that lasted less than one month	To treat a long-term health condition (one that lasted more than one month) or its symptoms	To improve well-being	Other (Please specify)	Very Somewhat Not at all Don't know		
Herbs/Herbal Medicine	1							
Vitamins/Minerals	,							
Homeopathic remedies								
Other Supplements	,							

4. Self Help Practices

	on n the		Please indicate	to your <u>last</u> use of the yone).	practice?				
Have you used any of the following self-help practices in the last 12 months?	Yes No	of times practions on the	For an acute illness/condition, one that lasted less than one month	To treat a long-term health condition (one that lasted more than one month) or its symptoms	To improve well-being	Other (Please specify the other reason)	Very Somewhat Ont at all On't know		
Meditation									
Yoga									
Qigong									
Tai Chi									
Relaxation techniques									
Visualization									
Attended traditional healing ceremony									
Praying for own health									
Specified option:									
Other (please specify):									

B2. Italy

International CAM Questionnaire (I-CAM-Q)

raccomandato per l'uso in studi di Medicine non Convenzionali versione auto-somministrata, in Italiano

1) CONSULTAZIONE DI VARI TIPI DI PROFESSIONISTI DELLA SALUTE (medici e non medici, che forniscono cure convenzionali o non convenzionali) DURANTE L'ULTIMO ANNO.

Nel caso lei abbia consultato uno o più <u>medici</u> utilizzi solo la riga 1 e quindi passi a pagina 2. Nel caso lei abbia consultato uno o più professionisti <u>non medici</u> utilizzi una (o più di una) delle righe da 2 a 9 e quindi passi a pagina 3.

	Ha consultato uno o più d'uno dei seguenti	na consultato 3 mesi?	ha con (mare Per un problema	problema di salute Der Altro motivo						er lei sto sola ozioni)
	professionisti durante gli ultimi 12 mesi?	Si No Quante volte lo ha consultato durante gli ultimi 3 mesi?	acuto (malattia o sintomo che durava da meno di un mese)	cronico (malattia o sintomo	Per migliorare il suo benessere	Altro motivo (si prega di specificare quale)	Molto	Abbastanza	Per nulla	Non so
1.	Medico									
2.	Chiropratico / Osteopata									
3.	Omeopata									
4.	Agopuntore									
5.	Erborista / Fitoterapeuta									
6.	Guaritore spirituale (
7.	Opzione specificata:									
8.	Altro: (specificare)									
9.	Altro: (specificare)									

2) TERAPIE NON CONVENZIONALI FORNITE DA MEDICI

(Alcuni medici prescrivono o praticano sia terapie convenzionali che non convenzionali).

ATTENZIONE: SE LEI <u>NON</u> HA CONSULTATO UN MEDICO DURANTE GLI ULTIMI 12 MESI SALTI QUESTA PAGINA E PASSI ALLA PAGINA 3 (DOMANDA 17).

	Ha ricevuto qualcuna delle seguenti terapie non convenzionali da parte di un medico durante gli ultimi 12 mesi?		QUante volte lo ha consultato durante gli ultimi 3 mesi?	quale ha	Per un problema di salute cronico (malattia o sintomo che durava	o il medico <u>l'</u> a delle quatt Per migliorare	Altro motivo (si prega di specificare	E' sta consi media (marc delle	ultare co? care <u>u</u>	ques una s	sto
		is S	정류	un mese)	un mese)			Ž	₹	<u> </u>	ž
10.	Terapie manuali (osteopatia, chiropra- tica, manipolazioni, etc)										
11.	Omeopatia										
12.	Agopuntura										
13.	Fitoterapia (piante medicinali)										
14.	Cure spirituali										
15.	Altro (opzione specificata)										
16.	Altro (specificare):										

3) USO DI PIANTE MEDICINALI E SUPPLEMENTI DIETETICI (comprese compresse, capsule e preparazioni liquide)

	Day since your della cata your	Usa <u>abitualmente</u> questo prodotto?	Per favore quale utili (marca Per un problema	Ha trovato utile questo prodotto? (marcare <u>una sola</u> <u>delle quattro opzion</u>			otto? sola			
	Per ciascuna delle categorie elencate qui sotto, la preghiamo di elencare da uno a tre prodotti che ha usato negli ultimi 12 mesi.	Usa <u>al</u> S duestr	di salute acuto (malattia o sintomo che durava da meno di un mese)	di salute cronico (malattia o sintomo che durava da più di un mese)	Per mi- gliorare il suo benes- sere	Altro motivo (si prega di specificare quale)	Molto	Abbastanza	Pe nulla	Non so
Piante	Medicinali									
17.										
18.										
19.										
Vitami	ne/Minerali			1						
20.										
21.										
22.										
Rimed	i Omeopatici			'	,		,			
23.										
24.										
25.										
Altri pı	rodotti o integratori alimentari									
26.										
27.										
28.										

4) PRATICHE DI AUTO-CURA

		esi?	per la qua	La preghiamo di indicare la <i>principale</i> ragione per la quale ha utilizzato questa pratica l'ultima volta (marcare <i>una sola delle quattro opzioni</i>)						uto
	Ha praticato qualcuna delle seguenti pratiche di auto-cura durante gli ultimi 12 mesi?	~ ⊂	Per un problema di salute acuto (malattia o sintomo che durava da meno di un mese)	Per un problema di salute cronico (malattia o sintomo che durava da più di un mese)	Per migliorare il suo benessere	Altro motivo (si prega di specificare quale)		quati		OS CON
29.	Meditazione									
30.	Yoga									
31.	Qigong									
32.	Tai Chi									
33.	Tecniche di rilassamento									
34.	Visualizzazioni									
35.	Partecipazione ad un rito di guarigione () L'uso di pratiche spirituali, come la preghiera, allo scopo di guarire o curare una malattia. Ciò include la cura mediante la fede, ma anche pratiche di cura che non prevedano il ricorso ad una divinità esterna.									
36.	Preghiera per la propria salute									
37.	Altro (opzione specificata)									
38.	Altro (si prega di specificare):									

B3. Spain

Cuestionario Internacional de Medicina Alternativa y Complementaria (I-CAM-Q):

El siguiente conjunto de preguntas trata sobre los tipos de profesionales de la salud que usted puede haber visitado en los últimos 12 meses. Para cada profesional que ha visitado en los últimos 12 meses, también le preguntaremos la razón de la visita y lo útil que fue ésta. Comencemos. La primera pregunta es...

nor clobababababababababa	e que fesional sesem	Por favor, indiq	lue la razón <u>princi</u> <u>por últi</u> (Escoja sólc	razón <i>principal</i> por la que <u>por última vez</u> (Escoja sólo una opción)	Por favor, indique la razón <u>principal</u> por la que visitó al profesional <u>por última vez</u> (Escoja sólo una opción).	¿Cómo de útil fue para usted la atención recibida? (Escoia sólo una)
,0	Sí Número de vece visitó a este prof en los últimos 3	Debido a una per en enfermedad/ es se	Para tratar una enfermedad/pro ceso o síntomas de mas de un mes de duración	Para mejorar su bienestar	Otra (Por favor, especificar cuál)	Muy útil Poco útil Nada útil
]					

TRATAMIENTOS COMPLEMENTARIOS RECIBIDOS POR UN MÉDICO

SI USTED NO HA VISITADO A UN MÉDICO EN LOS ÚLTIMOS 12 MESES, PASE A LA PREGUNTA 14.

Algunos médicos proporcionan tratamientos complementarios, además de convencionales. En esta sección se le preguntará acerca de los distintos tipos de tratamientos que usted pudo haber recibido por parte de su médico

	Ha recibido usted alguno	ne otne	Por favor, in	dique la razón <u>principal</u> por la tratamiento <u>por última vez.</u> (Escoja sólo <i>una</i> opción).	e la razón <u>principal</u> por la atamiento <u>por última vez</u> (Escoja sólo <i>una</i> opción)	Por favor, indique la razón <u>principal</u> por la que recibió este tratamiento <u>por última vez.</u> (Escoja sólo <i>una</i> opción).	¿Cómo de útil fue para usted el tratamiento recibido
	por to en los ?		Para tratar una enfermedad/ proceso agudo, que duró menos de un mes	Para tratar una enfermedad/pr oceso o síntomas de más de un mes de	Para mejorar su bienestar	Otra: (Por favor, especifique cuál)	wy útil (Escoja sólo una) y útil (Booga sólo una) sda útil sabe
80	Manipulación	en		duracion			rd
6	Homeopatía						
10.	Acupuntura						
11.	Plantas medicinales						
12.	Sanamiento espiritual						
13.	Otro (por favor, especifique cuál):						

USO DE PLANTAS MEDICINALES Y SUPLEMENTOS DIETÉTICOS (incluyendo comprimidos, cápsulas y líquidos)

Plantas	Por favor, cite para cada una de las siguientes categorías hasta un total de tres productos que usted haya utilizado en los últimos 12 meses.	Set Suffiliza usted este producto N actualimente?	Por favor, in Para tratar una enfermedad/ proceso agudo, que duró menos de un mes	dique la razón principal por la que producto la última vez que lo hizo (Escoja sólo una opción). Para tratar una enfermedad/pr Para coceso o sintomas de sintomas de sintomas de duración	incipal por a vez que le una opción una opción para mejorar su bienestar	Por favor, indique la razón <u>principal</u> por la que utilizó este producto la última vez que lo hizo (Escoja sólo <i>una</i> opción). Para tratar una una enfermedad/pr enfermedad/pr enfermedad/pr esso agudo, sintomas de sintomas de un mes de un mes de unación	Como de útil calificaria usted este producto? (Escoja solo una opción) Nu co da o o o o o o o o o o o o o o o o o o
14.							
15.							
16.							
Vitamin	Vitaminas/Minerales						
17.							
18.							
19.							
Remedi	Remedios homeopáticos						
20.							
21.							
22.							
Otros S	Otros Suplementos						
23.							
24.							
25.							

PRÁCTICAS DE AUTOAYUDA

		iones que práctica meses.	Por favor, in	dique la razón <i>principal</i> por la que práctica la última vez que lo hizo (Escoja sólo <i>una</i> opción).	ue la razón <u>principal</u> por la ctica la última vez que lo l (Escoja sólo <i>una</i> opción). ra tratar	Por favor, indique la razón <u>principal</u> por la que utilizó esta práctica la última vez que lo hizo (Escoja sólo <i>una</i> opción).	¿Cómo de útil calificaría usted esta práctica? (Escoja sólo una
	cha unizato arguna de las siguientes prácticas de autoayuda en los últimos 12 meses?	SI No Número de ocas ha utilizado esta ha utilizado esta en los últimos 3	Para tratar una enfermedad/ proceso agudo, que duró menos de un mes	una enfermedad/ proceso o sintomas de más de un mes de duración	Para mejorar su bienestar	Otra (Por favor, especifique cuál)	Muy útil oco útil Nada útil Mo lo sabe
26.	Meditación						
27.	Yoga						
28.	Qigong (Chi-Kung)						
29.	Tai Chi						
30.	Técnicas de relajación						
31.	Visualización						
32.	Ceremonia asistida de curación tradicional						
33.	Rezar por su propia salud						
34.	Pidió a otros que rezaran por usted:						
35.	Otra (por favor, especifique cuái):						

B4. Romania

CHESTIONARUL INTERNAȚIONAL MCA (I-CAM-Q) REALIZAT DE NAFKAM: RECOMANDAT PENTRU STUDII DE MEDICINĂ COMPLEMENTARĂ SI ALTERNATIVĂ (MCA)Versiunea auto-administrată

1. Adresabilitatea catre serviciile de sănătate: problemele de sănătate pot fi abordate de o varietate de furnizori de servicii de sănătate complementare si conventionale

Ati apelat la oricare dintre următorii furnizori în ultimele 12 luni?			apelat la , în ultimele	a	rificati motivul <u>pr</u> pelat la furnizor ifati <u>doar una</u> dir	ultima oara		faptu	ıl că a furni	ti ape	ijutat lat la
	DA	NU	De câte ori ati apelat la acest furnizor, în ultimele 3 luni?	Pentru o afectiune/boală acută, care a durat mai putin de o lună	Pentru a trata o afectiune cronică (care a durat mai mult de o lună) ori simptomele acesteia	Pentru a îmbunătăti starea de sănătate	Altul (specificati alt motiv)	Foarte mult	Oarecum	Deloc	Nu stiu
MEDIC											
TERAPEUT MANUAL			_								
HOMEOPAT											
ACUPUNCTOR											
FITOTERAPEUT			_								
VINDECATOR SPIRITUAL**											
OPTIUNE SPECIFICĂ:											
ALTA (VÅ RUGAM SPECIFICATI):			_								
ALTA (VÀ RUGAM SPECIFICATI):			_								

^{*}Terapeut manual – practicant certificat de masaje, manipulari, chiropractica, osteopatie

^{**} Vindecator spiritual – preot care foloseste rugaciunea individuala sau colectiva si ritualuri de vindecare specifice (maslu)

2. Tratamente complementare aplicate de către medici (dr) Dacă <u>nu</u> ati fost văzut(ă) de un medic în ultimele 12 luni, vă rugam treceti la întrebarea nr. 3

Unii medici oferă atât tratamente complementare cât și convenționale

Ati beneficiat de vreun tratament complementar dintre următoarele, efectuat de către un medic, în			i beneficiat timele 3	pri	ecificati motivul mit <u>ultima dată</u> a vifati <u>doar una</u> di	cest tratamer	ıt	sa pi din ?	imiti (partea	tratam	ajutat ientul icului
ultimele 12 luni?	DA	NU	De câte ori a⊐i benefic de acesta, în ultimele 3 hni?	Pentru o afectiune/boală acută, care a durat mai putin de o lună	Pentru a trata o afectiune cronică (care a durat mai mult de o lună) ori simptomele acesteia	Pentru a îmbunătăti starea de sănătate	Altul (specificati motivul)	Foarte mult	Oarecum	Deloc	Nu 🗆 tiu
TERAPIE MANUALA											
HOMEOPATIE			_								
ACUPUNCTURĂ			_								
PLANTE MEDICINALE (FITOTERAPIE)			_								
VINDECARE SPIRITUALĂ**			_								
OPTIUNE SPECIFICĂ:			_								
ALTA (VÅ RUGAM SPECIFICATI):			_								

^{**} Vindecare spirituala – practicata de un preot care foloseste rugaciunea individuala sau colectiva si ritualuri de vindecare specifice (maslu)

3. Utilizarea plantelor medicinale si a suplimentelor alimentare, incluzând comprimatele, capsulele si formele lichide

	in prezent acest produs?		bifati <u>doar una</u> di	<u>ultima oară</u> ntre variante)	(bifa vari	iti <u>doar</u> ante)	r una d	intre
DA	NU	Pentru o afectiune/boal ă acută, care a durat mai putin de o lună	Pentru a trata o afectiune cronică (care a durat mai mult de o lună) ori simptomele acesteia	Pentru a îmbunătăti starea de sănătate	Altul (specificati motivul)	Foarte mult	Oarecum	Deloc	Nu Otiu
UPL	IMENTE	DIN PLANTE M	EDICINALE						
Έ						•			
			ă acută, care a durat mai putin de o lună CUPLIMENTE DIN PLANTE M CUP	ă acută, care a durat mai mult de o lună) ori simptomele acesteia UPLIMENTE DIN PLANTE MEDICINALE	ă acută, care a durat mai mult de o lună) ori simptomele acesteia Description Des	ă acută, care a durat mai mult de o lună) ori simptomele acesteia UPLIMENTE DIN PLANTE MEDICINALE UPLIMENTE DIN PLANTE MEDICINALE UPLIMENTE DIN PLANTE MEDICINALE UPLIMENTE DIN PLANTE MEDICINALE			

4. Practici de auto-ajutorare

Ati utilizat vreuna dintre practicile următoare, în ultimele 12 luni?			folosit a, în	utilizat <u>ultim</u> (b	cificati motivul <u>p</u> <u>a dată</u> aceasta pr vifati <u>doar una</u> di	actica de aut	o-ajutorare	acea	sta tica(B	lt v-a : ifati	doar
	DA	NU	De câte ori ati folosit aceasta practica, în ultimele 3 luni?	Pentru o afectiune/boală acută, care a durat mai putin de o lună	Pentru a trata o afectiune cronică (a durat mai mult de o lună) ori simptomele acesteia	Pentru a îmbunătăti starea de sănătate	Altul (specificati motivul)	Foarte mult	Oarecum	Deloc	Nu stin
MEDITATIE			_								
YOGA			_								
QIGONG			_								
TAI CHI			_								
TEHNICI DE RELAXARE			_								
VIZUALIZARE***			_								
PARTICIPARE LA CEREMONII TRADITIONALE DE VINDECARE			_								
RUGĂCIUNEA PENTRU SĂNĂTATEA PROPRIE			_								
OPTIUNE SPECIFICĂ:			_								
ALTA (VĂ RUGAM SPECIFICATI):			_								

B5. Netherlands

Voor u ligt een vragenlijst om het gebruik van complementaire en alternatieve behandelwijzen te inventariseren.

Het gaat erom om in onderzoeksprojecten een idee te krijgen welke vormen van complementaire en alternatieve behandelwijzen gebruikt worden en hoe vaak deze worden toegepast.

De vragenlijst is onderverdeeld in vier thema's. Bij elk thema treft u een tabel met vragen aan, voorgedrukte antwoordmogelijkheden met hokjes om het antwoord dat van toepassing is, aan te kruisen. Leest u svp de bovenste regel van iedere tabel zorgvuldig door, omdat hierin uitgelegd wordt waar het bij de betreffende vraag om gaat en begint u dan pas met de beantwoording van de vragen.

De gegevens uit de vragenlijst worden volgens de wettelijke bepalingen van gegevensbescherming verzameld en uitgewerkt en deze worden absoluut vertrouwelijk behandeld. De uitwerking van de enquete gebeurt anoniem!

1. Zorgaanbieders die u bezocht heeft. Voor uw klachten kunt u verschillende zorgaanbieder hebben bezocht, variërend van (huis)arts tot therapeuten die reguliere, complementaire of alternatieve behandelwijzen aanbieden.	/oor uw kl	achten kunt u vieden.	verschillende zorgaar	nbieder hebben bezo	ocht, variërend van (huis)arts tot therapeute	n die reguliere,
		Aantal	Geeft u svp de	Geeff u svp de hoofdreden op, waarom u de laatste keer de genoemde aanbieder hebt bezocht.	len op, waarom u de laatste ke aanbieder hebt bezocht.	eer de genoemde	Hoe nuttig was het bezoek bij deze
Hebt u in de afgelopen 12 maanden één van de volgende aanbieders bezocht?		maal waarin u in de	Bij een acute	Voor de behandeling van een chronische	-		aanbieder? (maar 1 mogelijkheid aankruisen)
	Ja Nee	afgelopen 3 maanden deze aanbieder bezocht.	ziekte/klacht (met een duur van minder dan 1 maand)	ziekte of de symptomen daarvan (met een duur van meer dan 1 maand)	ler ver betering van het algemeen welbevinden	Andere (svp benoemen)	Zeer nuttig Een beetje Helemaal niet ik weet het
Huisarts							
Homeopaat							
Acupuncturist							
Natuurgeneeskundige							
Spirituele genezer							
Osteopaat							
Chiropraktor							
Andere (graag aangeven welke):							

2. Door artsen toegepaste behandelingen op het gebied van complementaire en/of alternatieve behandelwijzen. Als u in de afgelopen 12 maanden niet bij een arts in behandeling bent geweest, gaat u dan svp verder met vraag 3 Sommige artsen bieden zowel complementaire, alternatieve als reguliere behandelingen aan.	ingen op h et bij een a nentaire, al	net gebied van co arts in behandel ternatieve als reg	omplementaire e ing bent gewees juliere behandelin	gebied van complementaire en/of alternatieve behandelwijzen. s in behandeling bent geweest, gaat u dan svp verder met vraa, natieve als reguliere behandelingen aan.	ehandelwijzen. erder met vraag 3		
			Geeff u svp o	Geeff u svp de <u>hoofdreden</u> op, waarom u de laatste keer de genoemde behandeling hebt gekregen.	<u>eden</u> op, waarom u de laatste k behandeling hebt gekregen.	keer de genoemde	Hoe nuttig was deze behandeling?
		Aantal maal dat u in de afgelopen 3	Rii oon acrito	Voor de behandeling van			(maar 1 mogelijkheid aankruisen)
Hebt u in de afgelopen 12 maanden één van de volgende behandelingen gekregen van een arts?	Ja Nee	maanden deze behandeling hebt gekregen	ziekte/klacht (met and duur van minder dan 1 maand)	ziekte of de symptomen daarvan (met een duur van meer dan 1 maaand)	Ter verbetering van het algemeen welbevinden	Andere (svp benoemen)	Zeer nuttig Een beetje ik weet het niet
Homeopathie							
Acupunctuur							
Natuurgeneeskunde							
Manuele Therapie							
Spirituele genezing							
Andere (graag aangeven welke):							
Andere (graag aangeven welke):							

 Gebruik van kruider druppels, zalven, etc). 	nmiddelen,	homeopathische	middelen en voedin	gssupplementen	Gebruik van kruidenmiddelen, homeopathische middelen en voedingssupplementen in welke vorm dan ook (bv. Tabletten, capsules, druppels, zalven, etc) .	(bv. Tabletten, capsules,
		Geeft u svp de	Geeff u svp de <u>hoofdreden</u> op, waarom u de laatste keer dit product hebt gebruikt	ı de laatste keer dit pr	oduct hebt gebruikt.	Hoe nuttig vond u dit product?
Geeff u svp voor elke hieronder genoemde categorie maximaal 3 producten op, die u in de afgelopen 12 maanden gebruikt hebt?	Gebruikt u o dit moment dit product?	Bij een acute ziekte/klacht (met een duur van minder dan 1	Voor de behandeling van een chronische ziekte of de symptomen daarvan	Ter verbetering van het algemeen welbevinden	Andere (svp benoemen)	(maar 1 mogelijkneid aankruisen) seetje maal niet et het
	nee nee	maand)	(met een duur van meer dan 1 maand)			Een b
Homeopathische middelen						
Kruiden/fytotherapeutische middelen	ldelen					
Vitaminen/Mineralen						
Andere supplementen						

4. Gebruik va	an zelfzc	Gebruik van zelfzorg methoden					
		Aantal keer waarin u in de afgelopen 3 maanden deze zelfzord	Geeft u svp de <u>hoo</u>	Geeft u svp de <u>hoofdreden</u> op, waarom u de laatste keer deze zelfzorg methode hebt beoefend?	de laatste keer deze efend?	e zelfzorg methode	Hoe nuttig vond u deze zelfzora methode?
Hebt u in de afgelopen		methode hebt aangewend					(maar 1 mogelijkheid aankruisen)
12 maanden één van de volgende zelfzorg methoden beoefend?	Ja Nee	dagelijks < dan 1x per maand Helemaal niet	Bij een acute ziekte/klacht (met een duur van minder dan 1 maand)	Voor de behandeling van een chronische ziekte of de symptomen daarvan (met een duur van meer dan 1 maand)	Ter verbetering van het algemeen welbevinden	Andere (svp benoemen)	Zeer nuttig Een beetje Helemaal niet k weet het niet
Meditatie							
Yoga							
Qigong							
Tai Chi							
Ontspannings- technieken							
Visualisatie							
Bidden voor de eigen Gezondheid							
Bijwonen van tradition. helende ceremonie							
Andere (svp methode noemen):							

B6. Hungary

NAFCAM Nemzetközi CAM kérdőív

A következő kérdéskörökben az egészségügyi szolgáltatók által nyujtott tevékenységi körökre kérjük a választ, amelyeket az elmult 12 hónapban igénybe vett Ön. Minden - az elmult 12 hónapban- igénybevett szolgáltatásnál kérjük jelölje meg az okot, és a terápia sikerességét is. Kezdjük és az első kérdés következik...

		Yes- Igen No- nem	Kérjük, jelöjle r	meg a legfőbb okát, hogy a szolgál (kérjük, csak egyet jelüőljön meg)	át, hogy a sz et jelűöljön r	Kérjük, jelöjle meg a legfőbb okát, hogy a szolgáltatót felkereste (kérjük, csak egyet jelüőljön meg)	
	Találkozás az alábbi területek szakembereivel az elmúlt 12 hónapban	Találkozások száma az elmúlt 3 hónapban?	A találkozás oka olyan akut megbetegedés, amely 1 hónapnál rövidebb ideje áll fenn?	Hosszabb ideje megbetegedés v. tünetek miatt volt szüksége a kezelése?	A jó közérzet kialakításáé rt	A jó Más okból özérzet (részletezze és ialakításáé pontositsa az okokat) t	Mennyire volt segitségére a szolgáltató? (csak egyet jelöljön meg) nagyon valamennyire egyáltalán nem nem tudom
1.	Orvos				×		egyáltalán nem
2.	Manuálterápeuta						
8.	Homeopata				×		egyáltalán nem
4.	Akupunktúrás szakember				x		nagyon
5.	Herbalist/ Fitoterápeuta						
6.	Prayer/ egyházi személy (ima)						
7.	Prayer/ egyházi személy (ima)						

KOMPLEMENTER KEZELÉSI MÓDOK, AMELYEKET ORVOSOK ALKALMAZTAK (MDS) Ha a paciens nem volt az elmult 12 hónapban orvosnál, lépjen a 179. o. kérdéshez

Néhány orvos konvencionális és komplementer terápiát is alkalmaz. A következő rész azokról a különböző kezelési formákról kérdezi Önt, amelyeket rendes családorvosa nyújthat az Ön számára.

Ī							
	Mennyire volt segitségére a szolgáltató terápiája? (csak egyet jelöljön meg) - nagyon - valamennyire - egyáltalán nem - nem tudom						
	Más okból részletezze és pontositsa az okokat)						
	A jó közérzet kialakításá- ért						
	Hosszabb ideje kartó megbetegedés v. tünetek miatt volt szüksége a kezelésre?						
	A találkozás oka hosszabb ideje megbetegedés, tantó amely 1 v. tűnetek miatt közérzet hónapnál volt szüksége a ért rövidebb ideje állkezelésre?						
Yes - IGEN No - NEM	r kapta et a ket az n?						
	Hányszo Ön ezek Ön ezek 12 hónapban családorvosa az utóbbi 3 alábbi kezelések közül? hónapba	Manupulativ technika	Homeopátia	Akupunktúra	Gyógynővények	Spirituális gyógyítás	Más (kérjűk pontosítsa!):
		1.	2.	3.	4.	5.	9.

Gyógynövények és táplálékkiegészítők használata

(tabletták, kapszulák, folyékony formátumú anyagok formájában)

		Jelenleg is hasznija a termékeket	Jelölje meg a ter	mékek használa) egyk	tának legfo	ontosabb okát I- (csak	Jelölje meg a termékek használatának legfontosabb okát !- (csak a termék alkalmazása? egyet!) (Jelöljön meg csak egy
	Az alábbi kategóriákon belül jelöljön meg legalább 3 terméket, amelyet használt az elmult 3 hónapban	Yes -IGEN	A szerek használatának oka olyan akut megbetegedés, amely 1 hónapnál rövidebb ideje áll fenn?	Hosszabb ideje tartó megbetegedés v. tünetek miatt volt szüksége a szerek használatára?	A jó közérzet kialakítás á- ért	Más okból (részletezze és pontositsa az okokat)	nagyon valamennyire egyáltalán nem nem tudom
Fitoterápiás s	Fitoterápiás szerek, gyógynövények						
1.	GUI Pi wan				x		valamennyire
2.							
3.							
Vitaminok, Nyomelemek	yomelemek						
4.	multivitamin, magne B6				x		valamennyire
5.							
9.							
Homeopátiás szerek	szerek						
7.	sedacur forte				×		nem tudom
8.							
9.							
Más kiegészítő szerek	tő szerek						
10.							
11.							
12.							

Önsegitő gyakorlatok

		Yes- IGEN No- NEM	Jelölje meg a l az ö	g a lefontosabb okát annak, amiért Ön a az öngyógyító gyakorlatot (csak egyet)	át annak, am corlatot (csa	Jelölje meg a lefontosabb okát annak, amiért Ön alkalmazta az öngyógyító gyakorlatot (csak egyet)	Mennyire volt hasznos a gyakorlat alkalmazása? (Jelöljön meg csak egy
	Alkalmazott-e Ön az alábbi önsegitő gyakorlatok közül valamelyiket az elmult 12 hónapban?	Hányszor alkalmazta Ön a gyakorlatot az elmult 3 hónapban?	Heveny megbetegedés miatt, amely rövidebb ideje áll fenn, mint 1 hónap	Hosszantartó egészségi állapot miatt amely több, mint 1 hónapja áll	A jó közérzet kialakításá- ért	Más okból (részletezze és pontositsa az okokat)	okot) nagyon valamennyire egyáltalán nem nem tudom
1.	Meditáció						
2.	Jóga						
3.	Csikung						
4.	TAIQI						
5.	Relaxációs technikák	30			x		nem tudom
9.	Vizualizáció						
7.	Tradicionális gyógyító szertartáson való részvétel						
.9	Saját egészségért történő ima						
9.	Mások kérése imára a felkérő egészségéért:						
10.	Other (please specify):						

B7. Instructions for completion

Health Practices Survey

This questionnaire is designed to help researchers understand the different types of health practices and remedies used by persons in the European Union.

There are 4 sections.

Before starting each section please read the top line of the table carefully as it explains what the section is about. Please use them to tell us about any other treatments you have used in the last 12 months

Not all people will be familiar with each of the types of items included on the questionnaire.

Some people will use very few of the practices or remedies listed.

We ask you to complete each question on the questionnaire.

In each case, you will be asked to indicate "yes" or "no" on whether you use the practice or remedy.

If you do not know what a particular question is asking about, then it is probable that you do not use the type of practice or remedy, so you should answer "no". If you answer "no", you should go on to the next line of the questionnaire.

If you answer "yes", you should continue with the other questions on the same line about that practice or remedy.

Your answers to all these questions are important to us, even if you respond "no" to many of the questions.

Thank you for helping us.

B8. Demographic questions

PERSONAL CHARACTERISTICS

The following questions are to provide us with some information that describes you. Please check the appropriate response for each question.

1.	What is your date of birth?
	Day Month Year
2.	Are you a man or a woman? man woman
3.	In which country were you born?
4.	In which country do you live now?
5.	What was the highest level of school that you completed? O level/CSE/Lowers A level/Highers Vocational qualification (NVQ, HND) University Degree (BSc/BA, MSc/MA, PhD) professional qualification
6.	In general, would you say your health is: Excellent Very good Good Fair Poor
(by Ic	you have a long-standing illness, disability or infirmity? Ing standing we mean anything that has troubled you over a period of time, or that is to affect you over a period of time) Yes No
	If Yes, what long-standing illness, disability of infirmity do you have?
10.	Do you have access to health services provided by governmental funds? yes No
11.	Do you have private health insurance? yes No

Appendix C. Self-complete Invitation pack



The development of a questionnaire about health care use.

Participant Information Sheet

You are invited to take part in a research study. Please take time to read this information sheet before deciding if you would like to take part.

What is the purpose of the study?

In collaboration with Universities from other European Union countries, we are testing a questionnaire about the use of different types of healthcare.

Why have I been chosen?

Because we are asking a wide variety of people about their opinions

What will happen if I decide to take part?

If you would like to take part, please complete the enclosed questionnaire and send it back to us at the University of Southampton using the pre-paid reply envelope.

We think it will take around 10 minutes to complete the questionnaire, but you may find it takes you a little less or a little more time.

What will happen if I don't want to take part, or want to withdraw?

Please don't feel under any pressure to take part – it is entirely your choice. You can withdraw at any time without consequence and you do not have to give a reason.

Is the information I provide confidential?

We ask you not to write your name on your questionnaires. That way we can make sure your answers to the questionnaires can be kept anonymous.

What if there is a problem?

We do not anticipate any problems. However, if the questionnaires raise any issues that cause you distress, please let us know so we may direct you to the appropriate support.

What will happen to the information I provide?

The findings will be used to refine our questionnaire

Who is funding the study?

The European Union are funding this study

Where can I find out some more information?

If you have more questions or would like more information, please contact:

Susan Eardley, Research Fellow

Complementary Medicine Research Unit, Aldermoor Health Centre, Aldermoor Close, Southampton SO16 5ST

Phone: 023 80241069. Email: S.Eardley@soton.ac.uk

Appendix D





The development of a questionnaire about health care use.

Participant Information Sheet

You are invited to take part in a research study at the University or Southampton. Please take time to read this information sheet before deciding if you would like to take part.

What is the purpose of the study?

In collaboration with Universities from other European Union countries, we are testing a questionnaire about the use of different types of healthcare.

Why have I been chosen?

You have been chosen because we are asking a wide variety of people about their opinions.

What will happen if I decide to take part?

If you would like to take part we will make an appointment for you to come to either the Department of Primary Care or the Hartley Library (your choice) to complete the questionnaire with the researcher who will also record and then transcribe an interview with you about what you thought about the questionnaire which will take about 45 minutes.

What will happen if I don't want to take part, or want to withdraw?

Please don't feel under any pressure to take part – it is entirely your choice. You can withdraw at any time without consequence and you do not have to give a reason.

Is the information I provide confidential?

We ask you not to write your name on your questionnaires. That way we can make sure your answers to the questionnaires can be kept anonymous. Your tape recorded interview and written-up transcripts will have any identifying characteristics removed to maintain your anonymity

What if there is a problem?

We do not anticipate any problems. However, if the questionnaires raise any issues that cause you distress, please let us know so we may direct you to the appropriate support.

What will happen to the information I provide?

The findings will be used to refine our questionnaire

Who is funding the study?

The European Union are funding this study

Where can I find out some more information?

If you have more questions or would like more information, please contact:
Susan Eardley, Research Fellow. Phone: 02380 241 069. Email: S.Eardley@soton.ac.uk
Complementary Medicine Research Unit, Aldermoor Health Centre, Aldermoor Close, Southampton
SO16 5ST

<u>D2.</u>

A Pilot Study of an International Questionnaire to Measure the use of Complementary and Alternative Medicine (I-CAM-Q)



Consent form V2 (270511)

Researcher: Susan Eardley

Please read the following statements and initial each box to show that you have read them. Please then write your name and the date and sign the form below.

Name		 Signature	
I agree to take part in	this study		
be deleted following	the end of the study		
identifying character	istics removed but that	the recordings will	
this recording will b	e typed up word-for-wor	d with	
I understand that the	interview will be audio-	recorded and that	
am free to withdraw	at any time without givir	g any reason	
I understand that my	participation is volunta	ry and that I	
satisfactorily			
consider the informa	tion, ask questions and	have had these answered	
		e had the opportunity to	
I confirm that I have	read and understood the	information sheet dates	

D3. I-CAM-Q Cognitive Interviews Guide

The researcher will begin by welcoming the participant, going through the information sheet, and obtaining written informed consent. The warm up task will then begin (more than one will be used if necessary to get participants comfortable with thinking aloud), followed by the I-CAM-Q cognitive interview.

Warm-up Task(s)

To get you used to speaking aloud as you think, I am going to ask you a question, and I'd like you to tell me what you are thinking as you try to answer it.

- 1. Try to visualize the place where you live, and think about how many windows there are in that place. As you count up the windows, tell me what you are seeing and thinking about.
- 2. How many hours do you spend working on a typical week?

I-CAM-Q Questions

Now I am going to show you a questionnaire. I'd like you to fill it in, and as you do so please give me a running account of what does through your mind as you are reading each question and deciding on your answer.

Prompts to use if the participant stops talking:

- Tell me more about what you're thinking
- Keep talking
- Can you say more about that

Targeted probes to use when participant has completed the questionnaire. Probes should be asked about each main question on the ICAMQ, and a selection of the sub-questions. The interviewer should be guided by the aims to 1) elicit rich information about how the participant interpreted the questions and 2) identify any problematic questions.

General probes:

- Can you tell me what you were thinking and feeling when you were looking at this?
- How did you go about answering that question?
- Was that easy or difficult to answer? Why?
- Why did you choose that answer?

Comprehension

- What does the term X mean to you? (For terms:)
- Can you tell me, in your own words, what the question is asking?
- How would you say that question to yourself?

Confidence Judgement

- How did you remember that?
- How well do you remember that?
- How sure of your answer are you?

Recall/Judgment

- What time period were you thinking about when you answered that question?
- What brought that to mind?

Response

- How did you feel about answering this question?
- Do you think some people might not give a true answer to this question?

Layout

What do you think about the way the questionnaire looks?

Appendix E. Cognitive interview data summaries

E1. UK summary of 10 cognitive interviews

TERMINOLOGY

Names of Therapies and Therapists

The respondents in the study did not know the meaning of some of the terms. The box below contains the terms that people had difficulty with.

Physician, homeopath/homeopathy, chiropractor, acupuncture, herbal medicine/herbalist, spiritual healer, manipulation, health condition, complementary treatments, well-being, self-help practices, Qi Gong, Tai Chi, Relaxation, Visualisation, acute/chronic, specified option/other, vitamins & minerals

'that I'm not familiar with, {the terms} cause I didn't know what they were.'

9 participants said that they did not understand what was meant by the term **physician** (Q1) and two suggested that it was confusing because it's in American usage, not the UK (also the American term 'check' rather than the British 'tick')

'it's an American word'

'it needs to be more tailored towards British users, it's not used in the UK'.

One participant felt that physician was an ambiguous term and open to individual interpretation and one person was confused because they had seen a nurse and didn't know whether that visit should be recorded under physician or 'other'.

A number of people were confused between questions one & two as they were felt to be very similar possibly suggesting that people didn't understand or remember or recognise the distinction between practitioners with and without bio-medical qualifications

'no, why have, why is it different to that section? Surely it's the same thing is it?'
Some respondents did not know what **homeopathy**, **acupuncture** or **herbal medicine** was and yet these are arguably the more prevalent CAM interventions.

'some of, some of it, homeopathy I don't even know what that is, so...urm...I guess I was a bit stumbled by that...'

One person did not understand the term **chiropractor** (Q1) yet this respondent was recruited to the study at a chiropractor's clinic lending weight to our findings that people are generally unaware of the formal terminology for CAM.

4 people were confused about manipulation (Q2), wondering if it meant massage or physiotherapy.

'manipulation....what does that mean exactly....massage'

The term **Qi Gong** (Q4) was queried by the most number of people as unfamiliar and many struggled to pronounce it.

"...what the hell's Qigong?...what's Qigong?...Qygong? keygong?"

'urgh...I don't even know how you say that so I'm gonna click no for that one...'

For people who took **homeopathy and herbal medicines**, some of them didn't know the name of the remedies they were taking and so had difficulties providing answers to question 3. Some weren't sure whether what they were taking counted as herbal medicine or should be recorded under the 'other' option. One person was not sure what **vitamins and minerals** were.

'Erm I will put under herbs and herbal medicine, I'm not sure if that's where you want to put it under. but erm the back flower remedy...'

Understanding Categories

A number of participants suggested that some terms were too broad and categories were not clearly specified

'The terms used eg. physician, spiritual healer are quite ambiguous and open to individual interpretation and thus you should make this more clear. Also you could specify with 'herbalist' what you mean 'eg. Chinese, western' to ensure you are clear about what you are trying to collect'

This was true even of the overarching category 'complementary medicine', in that one participant did not know what this meant and others questioned whether specific therapies that they had used (e.g. hypnotherapy) should be included within this category.

'I don't really know what complementary treatments are...if I'm honest...'

With regard to the **self-help practices**, terminology continued to be an issue and two people were confused about the meaning of this umbrella term and asked the interviewer for an explanation. One person suggested using more 'main stream' terms and one person referred to the practices as obscure.

'I mean um, certainly some are a bit more obscure aren't they that eh...um...(muttering), like this one here. (Interviewer: The Qigong, yeah)'

Two participants wanted to know if 'sleep' was included in the term **relaxation** whereas two other participants did not understand the distinctions between **relaxation**, **meditation** and **visualisation** and saw them as different words for the same thing.

In the self-practices item of the questionnaire 3 people assumed that sport and exercise were included in the specified option/other section and one person suggested that exercise ought to be specifically mentioned as a self-help category.

Reasons for Use

Acute and chronic conditions were often misunderstood in terms of the length of time to be considered one or the other. One participant was not sure what a chronic illness was and another wondered if a muscular strain was an acute illness. One person asked the interviewer if a slipped disc was a health condition.

'would you consider a slipped disc a health condition or is it more of an injury'

Several participants wanted to mark more than one option where they had to indicate the main reason they last saw a practitioner because they couldn't choose one reason above another. For example, one person consulted a practitioner about a long term condition but also went to improve wellbeing. Well-being itself was suggested to be too broad a term that needed defining, with one participant for example questioning whether this was specifically about psychological issues of anxiety and depression.

One person didn't tick their chronic health condition because they said that as they took medication for it, they didn't suffer from it any more.

'Other' Options

The **specified option/other category** was frequently misunderstood by participants who either thought it was a space to put an illness or didn't know what it referred to at all. one person recorded the name of their biomedical drug under 'specified option'.

'Though what's this with specified option and other option, other please specify. What are the two different things?'

Layout

A number of participants determined the layout as 'unclear' and 'muddly' and having 'quite a lot on the page'. They frequently missed bits because they didn't see something they ought to have completed for example

'oh I didn't even read it. There you go. I just didn't even read it'

The vertical columns at the top of each page proved highly unpopular, participants complained that it made the questionnaire hard to read. One person mentioned that it was very tempting to carry on ticking down the page for the first column thus missing the subsequent columns and the interviewers observed participants doing just that – ticking in the first column of each question and then missing out the additional questions about number of consultations, reasons for use, and satisfaction with use.

'Erm, the second column with the yes or no bit is on the side which makes it a bit harder to read erm so if is was I dunno horizontal that would make it easier'

'The biggest problem with the questionnaire is the layout. Writing that runs vertically is very hard to read!'

One participant commented that a person with dyslexia might have trouble completing it and that it needed to be more visually more interesting.

Memory and Choosing Response Options

Some participants were unsure of how to decide whether or not they were 'currently' using a particular form of healthcare. For example if one had used it in the previous weeks but not on the day of completion, should this count as 'current'? One participant explained that they answered no to whether they currently use a particular remedy "no, cause I've run out".

They also found it confusing to have to think about a twelve month period and then a 3 month time period and a number of people couldn't remember how many times they had seen a practitioner at all, said it was difficult to remember, people didn't keep account of how many times they'd been to a doctor etc. One person said that twelve months was a long time to think back over.

'I think with uh, a lot of these questionnaires, they need to know specific numbers of how many times you've been to doctors and things like that, and um, I can't always remember...'

Several people asked how to mark the answer boxes and whether they needed to tick a box that wasn't relevant to them. One person suggested that the questionnaire should state whether to use a tick or cross.

'Only, um...I think you need to put on here, how you want it marked, you know tick boxes ergh, crosses or tick, you have to specify, cause if people do it differently, I put crosses, cause years ago, if you got older people they'll all tick, they won't do crosses, you got a job to make them go over to crosses, and computers want crosses, cause computers only accept crosses'

Several other participants didn't think there was enough space to list all the vitamins they took and one participant noted that they were not asked to say where they had got their herbs and they were not sure if that was relevant but they felt it was interesting to know and also to understand how people get their information and make selections. One person mentioned that as a healthy person there wasn't much to fill in

One participant commented that where they had to rate how helpful the treatment had been there was too big a jump from 'very' to 'somewhat' and their real response would have been somewhere between those two categories.

Would participants fill in the ICAMQ in a postal survey?

The participants who were interviewed were asked if they would be prepared to complete the questionnaire if it had been sent to them in the post; half of them said they wouldn't. One person said they didn't fill in 'cold drop' questionnaires, another because it didn't look legitimate as it wasn't on University headed paper, and another that it was boring and plain to look at but they might have filled it in if it had coloured borders or asked more interesting questions. One person would only have completed it if they had been offered a free CAM treatment in return.

'I think if I received it in the post I would be less inclined to fill it in, I think maybe the reason why I filled it in was because it was accompanied by someone who'd come in, it was university of Southampton on the paper, and it seemed to be a more legitimate questionnaire, erm, I think if it had come in the post I may have disregarded it, for the reasons that I thought it was not necessarily legitimate, and didn't come from an organisation I was necessarily familiar with.'

E2. Italy - Summary of 10 cognitive interviews

General remarks:

Layout:

Vertical layout text is difficult to read.

A respondent thinks that it could be better if the questionnaire was more 'coloured' and find it a little too 'strict', that's a reason why it does not encourage people to answer. Some respondents suggested to reverse the position of questions and answers (so that questions could be horizontal and answers vertical), saying that it could be easier to answer this way.

Problems with definitions of 'acute ' and 'chronic illness'

Some respondents asked explanations about the definition of 'acute illness' because in their opinion an 'acute illness' is something that lasts even just one day and this is not clearly exposed in the answer.

A respondent asked if, for example, a strong headache that lasted just one day can be considered an 'acute illness' in particular if this problem didn't need a treatment.

About the definition of 'chronic illness' some respondents asked how many months are necessary to consider an illness 'chronic', for example something that affects for years like a neoplasia or hypertension or diabetes, or something that lasts weeks or months, for example infections like pneumonia.

Another problem concerns for some respondents how serious should be a health problem to be considered an illness, for example a respondents asked if a flu or a sore throat can be considered an acute illness or not.

Easiness and precision of preliminary remarks / questions:

 $Some\ respondents\ showed\ problems\ in\ understanding\ preliminary\ remarks\ and\ questions.$

Almost all of them read questions and answers two times before answering and seemed not really self-confident.

In particular after reading question 2 many respondents had an hesitation, not understanding if they had to answer all the questions of question 2 by saying "no" or if they have to skip question 2. Another frequent remark was about question 3: some respondents asked what to do if they didn't use medicaments, not understanding if they had to answer all the questions of question 3 by saying "no" or if they have to of skip question 3 leaving all boxes blank.

The same remark was made for question 4.

Respondents found really easy demographic information, even if two of them suggested using boxes and not lines to mark the answers.

All respondents really appreciated open ended questions.

Remarks about question 1 were:

Spiritual healer:

A respondent argued that in our country is really difficult to find someone that gives credence to a spiritual healer. Maybe this can be possible for 'less educated people'.

All respondents carefully read the enclosed definition of 'spiritual healer'.

Problems with definitions:

Some respondents did not know the difference among different caregivers, in particular between 'homeopath' and 'herbalist'.

Two respondents didn't understand the meaning of line 7.

Problems with questions:

Some respondents found difficult to answer the same question (for example: if they consulted a physician) remembering what they did in 3 different periods of time (12 months, 3 months, last time).

A respondent found that options suggested to answer the question about how helpful a therapy is/was are few.

Remarks about question 2 were:

See 'General remarks'.

A respondent didn't understand the difference between question 1 and question 2 about the 2 different kinds of physicians providing CAM.

Remarks about question 3 were:

See 'General remarks'.

Problems with definitions:

Some respondents asked about the meaning of the term 'usually'; they said they didn't undestand if it means 'everyday' or 'for a long period of time'.

A respondent was surprised that there were no lines about ordinary drugs.

<u>Problems with layout:</u>

Some respondents said that for each category there are few lines to answer (for example he used many more vitamines than 3 and had to choose only 3 vitamines to answer).

Remarks about question 4 were:

Problems with definitions:

Almost all respondents didn't exactly know the meaning of terms like Qigong and Thai- Chi and obviously it was because they didn'practice them.

There was confusion also about terms like 'meditation', 'relax', 'visualization', 'spiritual healing'. A respondent thought that somehow 'yoga' and 'meditation' were synonymous and found the answer difficult.

A respondent told that for her the difference between 'meditation' and 'relax' is that the first concerns 'mind' and is something 'active', while the second concerns 'body' and is something 'passive'.

Honesty in answers:

A respondent said that pray is something that concerns inner feelings and so some respondents might not tell the truth for personal reasons.

Other self-help practices

Some respondents suggested to introduce activities like sports, voluntary work, painting etc . as self-help practices categories.

Summary and recommendations:

- Improve the *layout*: no answer categories vertically printed, use of boxes instead of dots/lines to mark the answers, more lines to answer question 3.
- Explain the meaning of the terms 'acute/chronic illness' maybe using small examples.
- Use preliminary remarks (introductions) for each question in order to clarify if respondents have to anser with 'no' or skipp the question.
- Use some brief explanation for terms like *meditation and relax* that are confusing for some people.

E3 Spain – summary of 10 cognitive interviews

General remarks:

Unclarity about the meaning of complementary medicine and complementary treatments

- One half of respondents said that they did not know the meaning of "complementary medicine" or "complementary treatments". Alternative medicine seemed to be clearer to them.

Layout

- Each question on one page would be clearer: some of them missed to answer the final items of every question.
- Some categories are presented horizontally, other vertically. That is confusing, older people complained about this.

Missing an answer category

- 6 of the interviewed stated that the difference between somewhat and very is too big.

Instructions

- One of the interviewed missed some more clear instructions, or even a less scientific language (complementary medicine for example)

Comprehension

- Most of the interviewed did not read the questionnaire properly. Some started answering all the questions of question 2 by saying "no" instead of skipping question 2 when they had indicated in question 1 not having seen a physician in the last 12 months. Others answered NO to every question, instead of skipping it.
- Many of the responders did not answer how often they visited the given health care provider or how often they received a given treatment.
- Some of the responders chose more than one option when only one option was required (perhaps the questionnaire includes too many words, and people don't read it properly).

Question 1:

Unclarity about the type of physician

- Three respondents had the impression that the physician should be one who is specialised in CAM practices.

A physiotherapist is not mentioned in the questionnaire

- Few of the respondents missed a physiotherapist (in Spain is not CAM)

Unclarity about the terms

- 6 of them recognized terms like chiropractor, homeopath or herbalist.
- 4 of them did not know what meant the term chiropractor, homeopath or herbalist.
- None of them recognized the term "spiritual healer"

Question 2:

- 6 respondents recognized all the terms, except spiritual healing
- 3 of them recognized only manipulation, acupuncture and herbs
- One of them did not recognize manipulation

Question 3:

No remarks

Question 4:

Difficulty to answer the direct helpfulness of a self-help-practice

- 5 of the respondents found difficult to indicate the direct helpfulness of a self-help practice.

Understanding the terms

- Visualization and assisted ceremony weren't recognized by any of the respondents
- Qigong was not recognized by 4 of the respondents.

Summary and recommendations:

- The terms *complementary* medicine or *complementary* treatment do not seem to be very familiar to the respondents.
- The difference between "somewhat" and "very" helpful is too big.
- In question 4 it was difficult to define whether the treatment was *helpful*.
- Terms like "chiropractor", "spiritual healer", "visualization" or "traditional assisted healing ceremony" were not recognized by a significant number of respondents. At least for Spain, some more definitions should be provided with the questionnaire.
- Lay-out: some people said it was difficult to read if some answer categories are vertically printed, while others are horizontally.

E4. Romania – summary of 1- cognitive interviews

1. General remarks:

Terms

- One respondent said that he prefers the term complementary medicine instead of alternative medicine because he feels that alternative excludes allopathic medicine.
- One respondent with higher education considered that people with lower educational level might experiences difficulties in understanding the questionnaire.

Questionnaire lay-out

- Some questions and answer categories are vertically printed and this is confusing, especially for older people. Vertically written questions such as number of times one visited a health provider in the last 3 months were missed by some of the respondents.
- Font size was considered too small by 2 respondents.

Instructions reading

 Some respondents started answering all the categories of question 2 by saying "no" instead of skipping question 2 after indicating in question 1 they have not seen a physician in the last 12 months.

Sensible questions

 Some respondents have difficulties in remembering the number of times they used self-help practices during the last 3 months. The number of times they prayed for their own health was the most delicate question.

2. Remarks about question 1:

- One respondent considered that only the physician must be one who is specialised in CAM practices.

3. Remarks about question 2:

- One respondent considered the question as having an impersonal formulation.

4. Remarks about question 3:

- Some respondents had difficulties in classifying the product they used to a certain category.
- An older respondent did not understand what "other supplements" means.
- Some respondents had difficulties in answering how helpful herbs and vitamins are.
- One respondent is using herbal tea but as a preventive measure, and he cannot appreciate how helpful this is.

5. Remarks about question 4:

- It is difficult to indicate how helpful a self-help practice is. Some respondents said they use it as a preventive method.

- One respondent said that he uses more than one self-help practice and it is difficult to quantify which one is more helpful because a cumulative effect could occur.
- One respondent was unsure what visualisation means.

6. End questions about the ICAMQ:

- One respondent suggested the introduction of bioresonance and thermography questions.
- One respondent complained about the small font size used.
- One respondent suggested that we should develop the self-help part of the questionnaire.

7. Summary

- In some questions respondents have to switch from 12 months to 3 months and in question 3 to the present and some respondents missed that.
- In question 3 some respondents had difficulties in choosing 3 products if they used more.
- In questions 3 and 4 it is sometimes difficult to answer whether the treatment is helpful.
- Concerning the lay-out: some people said it was confusing that some questions and answer categories are vertically printed and the font size is too small.

E5. Netherlands – summary of 10 cognitive interviews

1. General remarks were:

Unclarity about the difference between complementary and alternative medicine

- One respondent said that the difference between complementary and alternative medicine might not be clear. Especially complementary is not very familiar.

Lay-out (see also the remarks under "not having read very well")

- Each question on one page would be clearer. It is confusing now that each question is on two pages.
- Some answer categories are vertically printed. That is confusing

Missing an answer category

- The question about how helpful a therapy is/was misses a possibility between very and somewhat. A suggestion is to add: reasonably. The difference between somewhat and very is too big.

Not having read very well

- The questionnaire was not read very well. Examples are: some started answering all the questions of question 2 by saying "no" instead of skipping question 2 when they had indicated in question 1 not having seen a physician in the last 12 months. One respondent made the suggestion that that happened, because there is not a clear heading in question 2. After the heading it should say:..., go on with question3.
- Another example is: questions 1 and 2 are about having seen a health provider in the last 12 months and after that is asked about the times one visited a health provider in the last 3 months. One of the respondents answered this question also for the last 12 months. One respondent said that it might help to separate these 2 questions with a fat line. Someone said that it is difficult to switch from 12 months to 3 months and then to the present. Another one said that this switching was very confusing.
- Another example is in question 3: someone filled in the remedies but forgot to answer the question: "do you use it now?"

Someone forgot in question 4 to fill in the frequency with which self-help practices were used. *Acute vs. Chronic illness/complaint*

- For some respondents it is difficult to see an acute illness as the same as an illness that lasts less than a month. One respondent did not indicate vague complaints as an acute or a chronic illness and answered: "to improve well-being". Another respondent had complaints that lasted more than 1 month, but she did not call this chronic. It started as an acute illness but lasted longer than 1 month. Probing for an example of a chronic disease, she said:" something like diabetes".
- Another respondent had difficulty in choosing between acute and chronic. The reason was that the complaint was an acute manifestation of a specific (chronic) pattern .Besides, it was a psychological complaint.

- Another respondent said that an acute illness must be very serious such as an inflammation of the lungs.
- One respondent had diabetes for 1 year; that is why he did not fill in: chronic.

Many different rubrics

- One respondent said that there are many different rubrics such as homeopathy, acupuncture etc. and then you are not so inclined to add another one.

2. Remarks about question 1:

To improve well-being

"To improve well-being" has different meanings for some respondents. One meant by saying to improve well-being that the health care provider was only used for referral. Another respondent meant that she had specific complaints that returned now and then and then she went to the doctor.

Unclarity about the type of physician

- One respondent had the impression that the physician must be one who is specialised in CAM practices.
- One respondent asked whether the dentist belongs to the whole list

Some CAM physicians are known as a specific therapist, but they also practice other kind of therapies

- One respondent was treated by a herbalist, but this therapist treated him with massage and relaxation techniques.

A dietician and a physiotherapist is not mentioned in the questionnaire

One respondent missed a dietician and a few missed a physiotherapist

3. Remarks about question 2:

For one respondent there was a hesitation to indicate one single visit to a physician as a treatment

4. Remarks about question 3:

Difficult to choose the right category

One respondent uses T-tree-oil and had difficulty to see to which category it belongs to. Another did not know to which category linseed-oil and valeriana belong. Another hesitates about propolis and echinaforce. Another respondent did not know about SRL-ointment; he thought it belongs to homeopathy.

Forgetting something:

- One respondent forgot to fill in all the vitamins that were used.

Difficulty to answer the direct helpfulness of a product

- Someone said that a homeopathic remedy was used now and then only for relief and not so much for direct helpfulness. Another person said that the vitamins and linseed-oil were only used for prevention. This respondent tells that propolis is meant for inflammation and echinaforce for the immune system

Unclarity about "last use"

- One respondent was not sure whether "last use" meant: last use in the past 12 months or in your whole life

The use of many more products than 3

One respondent used many different vitamins; he did not know which ones to fill in.

5. Remarks about question 4:

Difficulty to answer the direct helpfulness of a self-help-practice

- The same remark was made as in relation to question 3: it is difficult to indicate the direct helpfulness of a self-help practice. Sometimes it is used as prevention.
- One respondent changed the healthcare provider within a year by another one. It is difficult to say how helpful it was. The first one was not very helpful.

"Medicalisation" of self-help practices

- One respondent thinks that this question is too "medicalised" while self-help practices are practiced in the same way you practice sports. The question of how pleasant it is, might be better than how helpful it is.
- Someone said that you don't do these self-help practices, because you have specific complaints
- These self-help practices are meant to be preventive instead of helpful

Some self-help practices belong together; total packages of self-help practices.

- Remarks were made about yoga. For one respondent relaxation techniques and meditation are supposed to be included in yoga. Another respondent indicated to use relaxation techniques and said that breathing exercises and visualisation are supposed to be a part of relaxation techniques.
- One respondent mentioned mindfulness (mindfulness-based-stress reduction). This was on referral of the general practitioner. In this type of therapy hatha-yoga and meditation are included. It is difficult to fill in all the methods apart from each other.

The meaning of relaxation techniques, mindfulness:

- Answers on the question what respondents mean by relaxation techniques are: "sitting down and feeling your feet, muscles, breathing etc. with a duration of 0,5-5 minutes each time" Another one said: "in order to empty the mind; 5 minutes not thinking of anything, 5 minutes thinking of a problem, 5 minutes not thinking of anything and then back to the here and now".
- Probing the apprehension of meditation (included in mindfulness):" 3 minutes concentration on breathing, bodyscan a few times a week during 45 minutes";

Yoga (included in mindfulness): "exercises that are meant for improving suppleness, muscles, general physical condition + breathing exercises";

Visualisation (included in mindfulness): "seeing a beautiful environment where you feel at ease".

Sports, running, soccer and food is not in the questionnaire

- A few respondents mentioned healthy food, such as food with low glycemic index; more fish hand less meat.

- Precious stones
- One respondent wears precious stones. He does not know which ones. His girlfriend recommended these to him (his girlfriend is an alternative therapist/non-physician)

6. Summary and recommendations

- The term *complementary* medicine does not seem to be very familiar to the respondents. Anyway, it does not disturb their answering process.
- The difference between "somewhat" and "very" helpful is too big. The recommendation is to add: "reasonably"
- Terms as "acute" and "chronic" are confusing. These terms are understood in a different way by various respondents. The recommendation is to ask for illnesses/complaints that last less than 1 month and those that last more than one month.
- In some questions respondents have to switch from 12 months to 3 months and in question 3 to the present. The recommendation is to skip the last 3 months and to ask here also after the last 12 months.
- In question 3 it is unclear why only *3 products* are asked. In case the respondent does not fill in the right category, there might be a problem. The recommendation is not to limit the number of products.
- In question 3 and 4 it is difficult to tell whether the treatment is *helpful*. The recommendation is to ask a slightly different question: How helpful, do you think that this product/self-help practice is?.
- Concerning *the lay-out*: some people said it was confusing that some answer categories are vertically printed.

Appendix F. Missing data rates broken down by individual questionnaire item

Table F1. Missing data and use of providers in the last 12 months

		To	tal	l	JK	Ron	nania	lt.	aly	Sn	ain		her- nds
		n	%	n	%	n	%	n	, %	n	%	n	%
Have you seen a	Miss.	1	1%	1	2%	0	.0%	0	.0%	0	.0%	0	0
physician?	Yes	153	81%	33	66%	45	90%	33	82%	42	84%	31	62%
Have you seen a	Miss	9	5%	0	.0%	0	.0%	0	.0%	9	18%	0	0
chiropractor?	Yes	33	17%	15	30%	12	24%	1	2%	5	10%	3	6%
Have you seen a	Miss	16	8%	2	4%	0	.0%	0	.0%	14	28%	0	0
homeopath?	Yes	14	7%	1	2%	9	18%	2	5%	2	4%	15	30%
Have you seen an	Miss	13	7%	2	4%	0	.0%	0	.0%	11	22%	0	0
acupuncturist?	Yes	20	11%	2	4%	6	12%	2	5%	10	20%	5	10%
Have you seen a	Miss	14	7%	2	4%	0	.0%	0	.0%	12	24%	0	0
herbalist?	Yes	20	11%	1	2%	11	22%	3	7%	5	10%	1	2%
Have you seen a	Miss	14	7%	2	4%	0	.0%	0	.0%	12	24%	0	0
spiritual healer?	Yes	15	8%	.0%	.0%	13	26%	1	2%	1	2%	1	2%
Total	Miss	67	6%	9	1%	0	0	0	0	58	5%	0	0

Table F2. Missing data and use of physician-delivered CAM in past 12 months

												Net	ther-
		To	tal	U	IK	Rom	nania	lta	aly	Sp	ain	la	nds
		n	%	n	%	n	%	n	%	n	%	n	%
Manipulation	Miss.	6	4%	2	6%	0	0%	1	3%	3	7%	0	0
from a physician	Yes	39	26%	5	15%	11	24%	4	12%	19	45%	3	6%
Homeopathy from	Miss	15	10%	1	3%	0	0%	1	3%	13	31%	0	0
a physician	Yes	12	8%	1	3%	9	20%	1	3%	1	2%	6	12%
Acupuncture from	Miss	3	2%	2	6%	0	0%	0	0%	1	2%	0	0
a physician	Yes	21	14%	1	3%	5	11%	1	3%	14	33%	3	6%
Herbs from a	Miss	13	9%	2	6%	0	0%	0	0%	11	26%	0	0
physician	Yes	23	16%	0	0%	18	40%	2	6%	3	7%	2	4%
Spiritual healing	Miss	15	10%	4	12%	0	0%	0	0%	11	26%	0	0
from a physician	Yes	15	10%	0	0%	13	29%	1	3%	1	2%	0	0
Total	Miss	52	7%	11	7%	0	0%	2	1%	39	19%	0	0
	expect	765		165		225		165		210			

Table F3. Responses to Question 2 by participants who had reported not seeing a physician

		T	otal		UK	Ro	mania	I	taly	S	pain
		n	%	n	%	n	%	n	%	n	%
Manipulation	Correctly skipped	11	34%	9	56.3%	0	.0%	0	.0%	2	50.0%
from a	Yes	5	16%	2	12.5%	2	40.0%	1	14.3%	0	.0%
physician	No	16	□0	5	31.3%	3	60.0%	6	85.7%	2	50.0%
	Total responding	21	66%	7	43.8%	5	100.0%	7	100.0%	2	50.0%
Homeopathy	Correctly skipped	11	34%	9	56.3%	0	.0%	0	.0%	2	50.0%
from a	Yes	0	0%	0	.0%	0	.0%	0	.0%	0	.0%
physician	No	21	66%	7	43.8%	5	100.0%	7	100.0%	2	50.0%
	Total responding	21	66%	7	43.8%	5	100.0%	7	100.0%	2	50.0%
Acupuncture	Correctly skipped	11	34%	9	56.3%	0	.0%	0	.0%	2	50.0%
from a	Yes	0	0%	0	.0%	0	.0%	0	.0%	0	.0%
physician	No	21	66%	7	43.8%	5	100.0%	7	100.0%	2	50.0%
	Total responding	21	66%	7	43.8%	5	100.0%	7	100.0%	2	50.0%
Herbs from a	Correctly skipped	11	34%	9	56.3%	0	.0%	0	.0%	2	50.0%
physician	Yes	1	3%	0	.0%	1	20.0%	0	.0%	0	.0%
	No	20	63%	7	43.8%	4	80.0%	7	100.0%	2	50.0%
	Total responding	21	66%	7	43.8%	5	100.0%	7	100.0%	2	50.0%
Spiritual healing	Correctly skipped	12	38%	10	62.5%	0	.0%	0	.0%	2	50.0%
from a	Yes	1	3%	0	.0%	1	20.0%	0	.0%	0	.0%
physician	No	19	59%	6	37.5%	4	80.0%	7	100.0%	2	50.0%
	Total responding	20	63%	6	37.5%	5	100.0%	7	100.0%	2	50.0%

Table F4. Missing Data and Current Use of Herbal, Vitamin, Homeopathic, and Supplement Products

		To	tal	ι	JK	Rom	nania	lt	aly	Sp	ain	Nethe	erlands
		n	%	n	%	n	%	n	%	n	%	n	%
	Miss	3	4%	1	2.%	2	4.%	0	0.%	0	0.%	0	0
Herbs 1	Yes	39	54%	7	14.%	t??4	42.%	4	10.%	7	14.%	3	75%
	No	30	42%	17	34.%	4	8.%	5	12%	4	8.%	1	25%
	Miss	3	8%	1	2.%	2	4.%	0	0.%	0	0.%	0	0
Herbs 2	Yes	19	51%	4	8.%	12	24.%	1	2.5%	2	4.%	0	0
	No	15	41%	5	10.%	3	6.%	4	10.%	3	6.%	1	1%
	Miss	3	13%	1	2.%	1	2.%	0	0.%	1	2.%	0	0
Herbs 3	Yes	10	42%	1	2.%	6	12.%	1	2.5%	2	4.%	0	0
	No	11	46%	5	10.%	4	8.%	2	5.%	0	0.%	0	0
\	Miss	4	6%	2	4.%	2	4.%	0	0.%	0	0.%	0	0
Vitamin	Yes	38	55%	15	30.%	11	22.%	4	10.%	8	16.%	23	88%
1	No	27	39%	17	34.%	3	6.%	4	10.%	3	6.%	3	12%
	Miss	3	13%	1	2.%	1	2.%	0	0.%	1	2.%	0	0
Vitamin	Yes	12	52%	4	8.%	6	12.%	0	0.%	2	4.%	8	80%
2	No	8	35%	6	12.%	2	4.%	0	0.%	0	0.%	2	20%
	Miss	1	8%	0	0.%	1	2.%	0	0.%	0	0.%	0	0
Vitamin	Yes	4	31%	1	2.%	2	4.%	0	0.%	1	2.%	2	50%
3	No	8	62%	5	10.%	3	6.%	0	0.%	0	0.%	2	50%
	Miss	2	5%	1	2.%	1	2.%	0	0.%	0	0.%	0	0
Hom 1	Yes	12	30%	3	6.%	4	8.%	3	7.5%	2	4.%	13	57%
	No	26	65%	16	32.%	7	14.%	0	0.%	3	6.%	10	43%
	Miss	4	22%	0	0.%	3	6.%	1	2.5%	0	0.%	0	0
Hom 2	Yes	0	0	0	0	0	0	0	0	0	0	10	83%
	No	14	78%	5	10.%	7	14.%	0	0.%	4.%	4.%	2	17%
	Miss	0	0	0	0	0	0	0	0	0	0	0	0
Hom 2	Yes	2	18%	0	0.%	2	4.%	0	0.%	0	0.%	3	60%
Hom 3	No	9	82%	4	8.%	4	8.%	1	2.5%	0	0.%	2	40%
	Miss	2	5%	2	4.%	0	0.%	0	0.%	0	0.%	0	0
Supp 1	Yes	18	49%	5	10.%	4	8.%	5	12%	4	8.%	2	1%
	No	17	46%	13	26.%	1	2.%	3	7.5%	0	0.%	0	0
	Miss	1	14%	0	0.%	1	2.%	0	0.%	0	0.%	0	0
Supp 2	Yes	3	43%	0	0.%	1	2.%	0	0.%	2	4.%	0	0
	No	3	43%	3	6.%	0	0.%	0	0.%	0	0.%	0	0
	Miss	0	0	0	0	0	0	0	0	0	0	0	0
Supp 3	Yes	0	0%	0	0.%	0	0.%	0	0.%	0	0.%	0	0
oupp 3	no	3	1%	3	6.%	0	0.%	0	0.%	0	0.%	0	0
Total Missi	ng	26	7%	9	6%	14	12%	1	3%	2	4%	0	
	Expe cted	354	7%	148	6%	121	12%	38	3%	47	4%	87	

Table F5. Missing data on use of self-care practices in the last 12 months

		То	tal	ι	JK	Ron	nania	It	aly	Sp	ain	Neth	erlands
		n	%	N	%	n	%	n	%	n	%	n	%
Meditation	Miss	10	5%	3	6.0%	0	.0%	0	.0%	7	14%	0	0
	Yes	32	17%	9	18%	6	12%	4	10%	13	26%	5	10%
Yoga	Miss	13	7%	4	8.0%	0	.0%	0	.0%	9	18%	0	0
	Yes	21	11%	6	12%	2	4.0%	6	15%	7	5	5	10%
Qi Gong	Miss	17	9%	6	12%	0	.0%	0	.0%	11	22%	0	0
	Yes	8	4%	3	6.0%	1	2.0%	0	.0%	4	8.0%	0	0
Tai Chi	Miss	15	8%	6	12%	0	.0%	0	.0%	9	18%	0	0
	Yes	10	5%	2	4.0%	0	.0%	3	7.5%	5	10%	1	2%
Relaxation	Mis	9	5%	2	4.0%	0	.0%	0	.0%	7	14%	0	0
	Yes	47	25%	12	24%	12	24%	6	15%	17	34%	5	10%
Visualisatio	Mis	17	9%	5	10%	0	.0%	0	.0%	12	24%	0	0
n	Yes	18	9%	9	18%	5	10%	0	.0%	4	8.0%	2	4%
Traditional	Miss	17	9%	6	12%	0	.0%	0	.0%	11	22%	0	0
Ceremony	Yes	9	5%	0	.0%	9	18%	0	.0%	0	.0%	0	0
Prayer	Miss	19	10%	4	8.0%	0	.0%	0	.0%	15	30%	0	0
	Yes	69	36%	8	16%	34	68%	12	30%	15	30%	5	10%
Total	miss	117	8%	36	9%	0	0%	0	0%	81	20%	0	0

Table F6. Number and proportion of missing responses for frequency of provider visits

		Total			UK		1	Romani	a		Italy			Spain		Ne	etherla	nds
	Exp	Miss	%	Ехр	Miss	%	Ехр	Miss	%	Ехр	Miss	%	Ехр	Miss	%	ехр	miss	%
Physician	153	37	24%	33	15	45%	45	1	2%	33	9	27%	42	12	29%	31	5	16%
Chiropractor	33	12	36%	15	9	60%	12	1	8%	1	0	0%	5	2	40%	3	0	0%
Homeopath	14		29%	1	0	0%	9	1	11%	2	1	50%	2	2	1%	15	1	7%
Acupuncturist	20	9	45%	2	2	1%	6	2	33%	2	1	50%	10	4	40%	5	0	0%
Herbalist	20	10	50%	1	1	1%	11	3	27%	3	1	33%	5	5	1%	1	0	0%
Spiritual Healer	15	5	33%	0	NA		13	5	38%	1	0	0%	1	0	0%	1	0	0%
Total	255	77	30%	52	27	52%	96	13	14%	42	12	29%	65	25	38%	56	6	11%

Exp = expected number of responses to the question 'how many times have you seen this provider'.

Table F7. Number and proportion of missing responses for frequency of physician-delivered CAM visits

		Total			UK			Romani	a		Italy			Spain		Ne	etherla	nds
	Ехр	Miss	%	Ехр	Miss	%	Ехр	Miss	%	Ехр	Miss	%	Ехр	Miss	%	ехр	miss	%
Manipulation from a physician	39	15	38%	5	4	80%	11	0	0%	4	4	1%	19	7	37%	3	1	33%
Homeopathy from a physician	12	3	25%	1	1	1%	9	0	0%	1	1	1%	1	1	1%	6	0	0%
Acupuncture from a physician	21	5	24%	1	1	1%	5	0	0%	1	1	1%	14	3	21%	3	0	0%
Herbs from a physician	23	5	22%	0	NA	NA	18	5	0%	2	0	1%	3	0	0%	2	0	0%
Spiritual healing from a physician	15	4	27%	0	NA	NA	13	2	15%	1	1	1%	1	1	1%	0	0	0%
Total	110	32	29%	7	6	86%	56	7	13%	9	7	78%	38	12	32%	14	1	7%

Exp = expected number of responses to the question 'how many times have you seen this provider'.

Table F8. Number and proportion of missing responses for frequency of self-care practices

		Total			UK			Romani	a		Italy			Spain		Ne	etherla	nds
	Ехр	Miss	%	Ехр	Miss	%	Ехр	Miss	%	Ехр	Miss	%	Ехр	Miss	%	ехр	miss	%
Meditation	32	19	59%	9	67%	67%	6	4	67%	4	1	25%	13	8	62%	5	1	20%
Yoga	21	9	43%	6	3	50%	2	1	50%	6	0	0%	7	5	71%	5	0	0%
Qi Gong	8	4	50%	3	1	33%	1	1	1%	0	NA		4	2	50%	0	0	0%
Tai Chi	10	5	50%	2	1	50%	0	NA		3	1	33%	5	3	60%	1	0	0%
Relaxation	47	25	53%	12	10	83%	12	5	42%	6	1	17%	17	9	53%	5	0	0%
Visualisation	18	10	56%	9	5	56%	5	2	40%	0	NA		4	3	75%	2	1	50%
Traditional Ceremony	9	4	44%	0	NA		9	4	44%	0	NA		0	NA		0	0	0%
Prayer	69	32	46%	8	6	75%	34	18	53%	12	2	17%	15	6	40%	5	0	0%
Total	214	108	50%	49	32	65%	69	35	51%	31	5	16%	65	36	55%	23	2	9%

Exp = expected number of responses to the question 'how many times have you seen this provider'.

Table F9. Missing and excess reasons for using each provider

Number of re	asons	Т	otal		UK	Ro	mania	I	taly	S	pain
sel	lected	n	%	n	%	n	%	n	%	n	%
	0	7	4.60%	1	3.%	4	8.90%	1	3.%	1	2.40%
Dhysisian	1	121	79.10%	29	87.90%	25	55.60%	27	81.80%	40	95.20%
Physician	2	19	12.40%	3	9.10%	10	22.20%	5	15.20%	1	2.40%
	3	6	3.90%	0	0.%	6	13.30%	0	0.%	0	0.%
Any incorrect res	ponse	32	20.90%	4	12.10%	20	44.40%	6	18.20%	2	4.80%
	0	4	12.10%	1	6.70%	2	16.70%	0	0.%	1	20.%
Chiropractor	1	19	57.60%	12	80.%	3	25.%	0	0.%	4	80.%
	2	10	30.30%	2	13.30%	7	58.30%	1	1.%	0	0.%
Any incorrect res	ponse	14	42.40%	3	20.%	9	75.%	1	1.%	1	20.%
	0	1	7.10%	0	2.%	0	0.%	0	0.%	1	50.%
Homoonoth	1	9	64.30%	1	1.%	6	66.70%	1	50.%	1	50.%
Homeopath	2	3	21.40%	0	0.%	3	33.30%	0	0.%	0	0.%
	3	1	7.10%	0	0.%	0	0.%	1	50.%	0	0.%
Any incorrect res	ponse	5	35.70%	0	0.%	3	33.30%	1	50.%	1	50.%
	0	5	25.%	0	0.%	1	16.70%	0	0.%	4	40.%
A	1	10	50.%	2	1.%	2	33.30%	0	0.%	6	60.%
Acupuncturist	2	4	20.%	0	0.%	2	33.30%	2	1.%	0	0.%
	3	1	5.%	0	0.%	1	16.70%	0	0.%	0	0.%
Any incorrect res	ponse	10	50.%	0	0.%	4	66.70%	0	0.%	4	40.%
	0	3	15.%	0	0.%	1	9.10%	0	0.%	2	40.%
Herbalist	1	11	55.%	1	1.%	4	36.40%	3	1.%	3	60.%
Herbalist	2	5	25.%	0	0.%	5	45.50%	0	0.%	0	0.%
	3	1	5.%	0	0.%	1	9.10%	0	0.%	0	0.%
Any incorrect res	ponse	9	45.%	0	0.%	7	63.60%	0	0.%	2	40.%
	0	4	26.70%	0	0.%	4	30.80%	0	0.%	0	0.%
Codellard	1	6	40.%	0	0.%	4	30.80%	1	1.%	1	1.%
Spiritual Healer	2	1	6.70%	0	0.%	1	7.70%	0	0.%	0	0.%
	3	4	26.70%	0	0.%	4	30.80%	0	0.%	0	0.%
Any incorrect res	ponse	9	60%	0	0.%	9	69%	0	0.%	0	0.%
Total miss resp	onses	24	9%	2	4%	12	13%	1	2%	9	14%
Total >1 resp	onses	55	22%	5	10%	40	42%	9	21%	1	2%
Total incorrec	t resp	79	31%	7	13%	52	54%	10	20%	10	15%

Table F10. Missing and excess reasons for using each therapy

Number of reas	ons	1	otal	ι	JK	Ron	nania	It	aly	S	pain
sele	cted	n	%	n	%	n	%	n	%	n	%
	0	2	4.40%	1	14.30%	1	7.10%	0	0.%	0	0.%
Manipulation	1	33	73.30%	5	71.40%	7	50.%	2	40.%	19	1.%
from a physician	2	9	20.%	1	14.30%	5	35.70%	3	60.%	0	0.%
	3	1	2.20%	0	0.%	1	7.10%	0	0.%	0	0.%
Any incorrect response	nse	32	12	26.70%	2	28.60%	7	50.%	2	40.%	0
Hamaanath	0	2	15.40%	0	0.%	2	20.%	0	0.%	0	0.%
Homeopathy	1	10	76.90%	1	1.%	7	70.%	1	1.%	1	1.%
from a physician	2	1	7.70%	0	0.%	1	10.%	0	0.%	0	0.%
Any incorrect response	nse	14	3	23.10%	0	0.%	3	30.%	0	0.%	0
	0	2	9.50%	0	0.%	1	20.%	0	0.%	1	7.10%
Acupuncture	1	14	66.70%	1	1.%	0	0.%	0	0.%	13	92.90%
from a physician	2	5	23.80%	0	0.%	4	80.%	1	1.%	0	0.%
	3										
Any incorrect response	nse	7	33.30%	0	0.%	5	1.%	1	1.%	1	7.10%
	0	2	9.50%	0	0.%	2	12.50%	0	0.%	0	0.%
Herbs from a	1	15	71.40%	0	0.%	10	62.50%	2	1.%	3	1.%
physician	2	4	19.%	0	0.%	4	25.%	0	0.%	0	0.%
	3										
Any incorrect response	nse	6	28.60%	0	0.%	6	37.50%	0	0.%	0	0.%
	0	3	18.80%	0	0.%	3	21.40%	0	0.%	0	0.%
Spiritual healing	1	5	31.30%	0	0.%	3	21.40%	1	1.%	1	1.%
from a physician	2	2	12.50%	0	0.%	2	14.30%	0	0.%	0	0.%
	3	6	37.50%	0	0.%	6	42.90%	0	0.%	0	0.%
Any incorrect response	nse	9	11	69%	0	0.%	11	79%	0	0.%	0
Total miss respon	nses	39	34%	2	22%	32	54%	4	40%	1	3%
Total >1 respo	nses	11	9%	1	11%	9	15%	0	0%	1	3%
Total incorrect	resp	28	24%	1	11%	23	39%	4	40%	0	0%

Table F11. Missing and excess reasons for using each product

Number of	reasons	Т	otal		UK	Ro	mania	ı	taly	S	pain
S	elected	n	%	n	%	n	%	n	%	n	%
	0	3	5.40%	1	11.10%	2	7.40%	0	0.%	0	0.%
Herbs 1	1	38	67.90%	6	66.70%	15	55.60%	7	77.80%	10	90.90%
Herbs 1	2	12	21.40%	2	22.20%	7	25.90%	2	22.20%	1	9.10%
	3	3	5.40%	0	0.%	3	11.10%	0	0.%	0	0.%
Any incorre	ct respe	18	32.10%	3	33.30%	12	44.40%	2	22.20%	1	9.10%
	0	4	12.50%	1	20.%	2	11.80%	0	0.%	1	20.%
Herbs 2	1	21	65.60%	4	80.%	10	58.80%	3	60.%	4	80.%
neros z	2	5	15.60%	0	0.%	3	17.60%	2	40.%	0	0.%
	3	2	6.30%	0	0.%	2	11.80%	0	0.%	0	0.%
Any incorr	ect resp	11	34.40%	1	20.%	7	41.20%	2	40.%	1	20.%
	0	2	10.50%	1	50.%	1	9.10%	0	0.%	0	0.%
Hawka 2	1	13	68.40%	1	50.%	7	63.60%	2	66.70%	3	1.%
Herbs 3	2	3	15.80%	0	0.%	2	18.20%	1	33.30%	0	0.%
	3	1	5.30%	0	0.%	1	9.10%	0	0.%	0	0.%
Any incorrect resp		6	31.60%	1	50.%	4	36.40%	1	33.30%	0	0.%
	0	9	15.80%	0	0.%	2	12.50%	1	12.50%	6	54.50%
Vitamin	1	39	68.40%	21	95.50%	10	62.50%	3	37.50%	5	45.50%
1	2	8	14.%	1	4.50%	3	18.80%	4	50.%	0	0.%
	3	1	1.80%	0	0.%	1	6.30%	0	0.%	0	0.%
Any incorr	ect resp	18	31.60%	1	4.50%	6	37.50%	5	62.50%	6	54.50%
\/itamain	0	3	16.70%	0	0.%	2	22.20%	0	0.%	1	33.30%
Vitamin 2	1	11	61.10%	5	83.30%	4	44.40%	0	0.%	2	66.70%
2	2	4	22.20%	1	16.70%	3	33.30%	0	2.%	0	0.%
Any incorr	ect resp	7	38.90%	1	16.70%	5	55.60%	0	0.%	1	33.30%
\/itami-	0	2	25.%	0	0.%	2	33.30%	0	0.%	0	0.%
Vitamin	1	4	50.%	1	1.%	2	33.30%	0	0.%	1	1.%
3	2	2	25.%	0	0.%	2	33.30%	0	0.%	0	0.%
Any incorre	ect resp	4	50.%	0	0.%	4	66.60%	0	0.%	0	0.%
	0	2	7.70%	0	0.%	1	20.%	1	12.50%	0	0.%
Supp 1	1	19	73.10%	8	88.90%	3	60.%	4	50.%	4	1.%
-	2	5	19.20%	1	11.10%	1	20.%	3	37.50%	0	0.%
Any incorr	ect resp	7	26.90%	1	11.10%	2	40.%	4	50.%	0	0.%

S 3	0	1	25.%	0	0.%	1	50.%	0	0.%	0	0.%
Supp 2	1	3	75.%	0	0.%	1	50.%	0	0.%	2	1.%
Any incorr	ect resp	1	25.%	0	0.%	1	50.%	0	0.%	0	0.%
	0	2	7.70%	0	0.%	1	8.30%	0	0.%	1	20.%
Hom 4	1	16	61.50%	6	1.%	4	33.30%	2	66.70%	4	80.%
Hom 1	2	7	26.90%	0	0.%	7	58.30%	0	0.%	0	0.%
	3	1	3.80%	0	0.%	0	0.%	1	33.30%	0	0.%
Any incorr	ect resp	10	38.50%	0	0.%	8	66.70%	1	33.30%	1	20.%
	0	1	7.10%	0	0.%	0	0.%	0	0.%	1	50.%
Hom 2	1	8	57.10%	1	1.%	6	60.%	0	0.%	1	50.%
	2	5	35.70%	0	0.%	4	40.%	1	1.%	0	0.%
Any incorr	ect resp	6	42.90%	0	0.%	4	40.%	1	1.%	1	50.%
Hom 2	1	4	57.10%	0	0.%	3	50.%	1	1.%	0	0.%
Hom 3	2	3	42.90%	0	0.%	3	50.%	0	0.%	0	0.%
Any incorr	ect resp	3	43%	0	0.%	3	50.%	0	0.%	0	0.%
Total incorre	ct	91	34%	8	13%	56	46%	16	42%	11	23%
to	otal 0	29	11%	3	5%	14	12%	2	5%	10	21%
to	otal >1	62	23%	5	8%	42	35%	14	37%	2%	2%

Table F12. Reasons for using each self-care practice

Number of i	reasons	Т	otal		UK	Ro	mania	I	taly	S	pain
s	elected	n	%	n	%	n	%	n	%	n	%
	0	4	12.50%	0	0.%	2	33.30%	0	0.%	2	15.40%
NA o ditation	1	24	75.%	9	1.%	1	16.70%	3	75.%	11	84.60%
Meditation	2	2	6.30%	0	0.%	1	16.70%	1	25.%	0	0.%
	3	2	6.30%	0	0.%	2	33.30%	0	0.%	0	0.%
Any incorrect re	esponse	8	25.%	0	0.%	5	83.30%	1	25.%	2	15.40%
	0	1	4.80%	0	0.%	0	0.%	1	16.70%	0	0.%
Yoga	1	19	90.50%	6	1.%	1	50.%	5	83.30%	7	1.%
	3	1	4.80%	0	0.%	1	50.%	0	0.%	0	0.%
Any incorrect re	esponse	2	9.50%	0	0.%	1	50.%	1	16.70%	0	0.%
Oi Cona	0	1	14.30%	1	33.30%	0	0.%	0	0.%	0	0.%
Qi Gong	1	6	85.70%	2	66.70%	0	0.%	0	0.%	4	1.%
Any incorrect re	esponse	1	14.30%	1	33.30%	0	0.%	0	0.%	0	0.%
T-: 6h:	1	9	90.%	2	1.%	0	0.%	2	66.70%	5	1.%
Tai Chi	2	1	10.%	0	0.%	0	0.%	1	33.30%	0	0.%
Any incorrect re	esponse	1	10.%	0	0.%	0	0.%	1	33.30%	0	0.%
	0	8	17.%	2	16.70%	4	33.30%	0	0.%	2	11.80%
	1	32	68.10%	9	75.%	3	25.%	5	83.30%	15	88.20%
Relaxation	2	3	6.40%	1	8.30%	1	8.30%	1	16.70%	0	0.%
	3	3	6.40%	0	0.%	3	25.%	0	0.%	0	0.%
	4	1	2.10%	0	0.%	1	8.30%	0	0.%	0	0.%
Any incorrect re	esponse	15	31.90%	3	25.%	9	75.%	1	16.70%	2	13.30%
	0	2	11.10%	0	0.%	1	20.%	0	0.%	1	25.%
Visualisation	1	13	72.20%	9	1.%	1	20.%	0	0.%	3	75.%
visualisation	2	1	5.60%	0	0.%	1	20.%	0	0.%	0	0.%
	3	2	11.10%	0	0.%	2	40.%	0	0.%	0	0.%
Any incorrect re	esponse	5	27.80%	0	0.%	4	80.%	0	0.%	1	25.%
	0	3	33.30%	0	0.%	3	33.30%	0	0.%	0	0.%
Traditional	1	2	22.20%	0	0.%	2	22.20%	0	0.%	0	0.%
Ceremony	2	1	11.10%	0	0.%	1	11.10%	0	0.%	0	0.%
	3	3	33.30%	0	0.%	3	33.30%	0	0.%	0	0.%
Any incorrect re	esponse	7	77.80%	0	0.%	7	77.80%	0	0.%	0	0.%
Prayer	0	13	19.10%	2	25.%	8	24.20%	0	0.%	3	20.%

1	45	66.20%	5	62.50%	16	48.50%	12	1.%	12	80.%
2	4	5.90%	1	12.50%	3	9.10%	0	0.%	0	0.%
3	5	7.40%	0	0.%	5	15.20%	0	0.%	0	0.%
4	1	1.50%	0	0.%	1	3.%	0	0.%	0	0.%
Any incorrect response	23	33.80%	3	37.50%	17	51.50%	0	0.%	3	20.%
Total incorrect	62	29%	7	14%	43	64%	4	13%	8	12%
total 0	32	15%	5	10%	18	27%	1	3%	8	12%
total >1	30	14%	2	4%	25	37%	3	10%	0	0%

Table F13. Missing data and helpfulness ratings for each provider

	How helpful?	Т	otal		UK	Ro	mania		Italy		Spain	Netl	nerlands
		n	%	n	%	n	%	n	%	n	%	n	%
Physician	Don't Know	3	1.9%	0	.0%	0	.0%	1	3.0%	2	4.7%	2	6%
	Not at all	4	2.6%	3	9.1%	0	.0%	0	.0%	1	2.3%	1	3%
	Somewhat	30	19.5%		24.2%	10	22.2%	10	30.3%	2	4.7%	6	19%
	Very	111	72.1%	20	60.6%	34	75.6%	20	60.6%	37	86.0%	17	55%
	Missing	6	3.9%	2	6.1%	1	2.2%	2	6.1%	1	2.3%	5	16%
Chiropractor	Don't Know	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0%
	Not at all	1	2.9%	0	.0%	0	.0%	0	.0%	1	20.0%	0	0%
	Somewhat	10	29.4%	0	.0%	6	50.0%	1	1.0%	3	60.0%	0	0%
	Very	21	61.8%	15	93.8%	5	41.7%	0	.0%	1	20.0%	3	1%
	Missing	2	5.9%	1	6.3%	1	8.3%	0	.0%	0	.0%	0	0%
Homeopath	Don't Know	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0%
	Not at all	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0%
	Somewhat	4	28.6%	0	.0%	2	22.2%	1	50.0%	1	50.0%	4	27%
	Very	10	71.4%	1	1.0%	7	77.8%	1	50.0%	1	50.0%	10	67%
	Missing	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	1	7%
Acupuncturist	Don't Know	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0%
	Not at all	1	5.0%	0	.0%	0	.0%	1	50.0%	0	.0%	0	0%
	Somewhat	6	30.0%	2	1.0%	3	50.0%	0	.0%	1	10.0%	0	0%
	Very	12	60.0%	0	.0%	2	33.3%	1	50.0%	9	90.0%	5	1%
	Missing	1	5.0%	0	.0%	1	16.7%	0	.0%	0	.0%	0	0%
Herbalist	Don't Know	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0%
	Not at all	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0%
	Somewhat	10	50.0%	1	1.0%	5	45.5%	2	66.7%	2	40.0%	0	0%
	Very	7	35.0%	0	.0%	5	45.5%	1	33.3%	1	20.0%	1	1%
	Missing	3	15.0%	0	.0%	1	9.1%	0	.0%	2	40.0%	0%	0%
Spiritual Healer	Don't Know	2	13.3%	0	.0%	1	7.7%	1	1.0%	0	.0%	0	0%
	Not at all	1	6.7%	0	.0%	1	7.7%	0	.0%	0	.0%	0	0%
	Somewhat	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0%
	Very	11	73.3%	0	.0%	10	76.9%	0	.0%	1	1.0%	1	1%
	Missing	1	6.7%	0	.0%	1	7.7%	0	.0%	0	.0%	0	0%
Total	Missing	13	5%	3	6%	5	5%	2	5%	3	5%	6	11%

Table F14. Missing data and helpfulness ratings for each therapy

How helpful?		1	Total .		UK	Ro	omania		Italy		Spain	Net	:herlands
		n	%	n	%	n	%	n	%	n	%	n	%
Manipulation	Missing	4	10.0%	1	20.0%	3	25.0%	0	.0%	0	.0%	1	33.33%
from a	Don't Know	2	5.0%	0	.0%	0	.0%	1	25.0%	1	5.3%	0	0.%
physician	Not at all	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Somewhat	15	37.5%	1	20.0%	5	41.7%	3	75.0%	6	31.6%	0	0.%
	Very	19	47.5%	3	60.0%	4	33.3%	0	.0%	12	63.2%	2	66.67%
Homeopathy	Missing	5	35.7%	0	.0%	4	40.0%	0	.0%	1	50.0%	0	0.%
from a	Don't Know	1	7.1%	0	.0%	0	.0%	1	1.0%	0	.0%	0	0.%
physician	Not at all	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Somewhat	2	14.3%	0	.0%	2	20.0%	0	.0%	0	.0%	3	50.%
	Very	6	42.9%	1	1.0%	4	40.0%	0	.0%	1	50.0%	3	50.%
Acupuncture	Missing	1	4.8%	0	.0%	1	20.0%	0	.0%	0	.0%	0	0.%
from a	Don't Know	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
physician	Not at all	0	.0%	0	.0%	,	.0%	0	.0%	0	.0%	0	0.%
	Somewhat	3	14.3%	1	1.0%	1	20.0%	0	.0%	1	7.1%	0	0.%
	Very	17	81.0%	0	.0%	3	60.0%	1	1.0%	13	92.9%	3	1.%
Herbs from a	Missing	4	17.4%	0	.0%	3	16.7%	0	.0%	1	33.3%	0	0.%
physician	Don't Know	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Not at all	2	8.7%	0	.0%	0	.0%	1	50.0%	1	33.3%	0	0.%
	Somewhat	6	26.1%	0	.0%	6	33.3%	0	.0%	0	.0%	0	0.%
	Very	11	47.8%	0	.0%	9	50.0%	1	50.0%	1	33.3%	2	1.%
Spiritual	Missing	2	13.3%	0	.0%	2	15.4%	0	.0%	0	.0%	0	0.%
healing from a	Don't Know	1	6.7%	0	.0%	0	.0%	1	1.0%	0	.0%	0	0.%
physician	Not at all	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Somewhat	1	6.7%	0	.0%	1	7.7%	0	.0%	0	.0%	0	0.%
	Very	11	73.3%	0	.0%	10	76.9%	0	.0%	1	1.0%	0	0.%
Total missing		16	14%	1	14%	13	22%	0	0%	2	5%	1	7%

Table F15. Missing data and helpfulness ratings for each product

			Total		UK	Ro	omania		Italy		Spain	Net	herlands
		n	%	n	%	n	%	n	%	n	%	n	%
Herbs 1	Missing	4	16.7%	0	.0%	3	15.8%	0	.0%	1	33.3%	2	50.%
	Don't Know	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Not at all	2	8.3%	0	.0%	0	.0%	1	50.0%	1	33.3%	0	0.%
	Somewhat	7	□9.2%	0	.0%	7	36.8%	0	.0%	0	.0%	0	0.%
	Very	11	45.8%	0	.0%	9	47.4%	1	50.0%	1	33.3%	2	50.%
Herbs 2	Missing	3	9.4%	1	20.0%	2	11.8%	0	.0%	0	.0%	0	0.%
	Don't Know	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Not at all	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Somewhat	12	37.5%	2	40.0%	7	41.2%	3	60.0%	0	.0%	0	0.%
	Very	17	53.1%	2	40.0%	8	47.1%	2	40.0%	5	1.0%	0	0.%
Herbs 3	Missing	2	10.5%	1	50.0%	1	9.1%	0	.0%	0	.0%	0	0.%
	Don't Know	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Not at all	1	5.3%	0	.0%	0	.0%	1	33.3%	0	.0%	0	0.%
	Somewhat	7	36.8%	1	50.0%	5	45.5%	0	.0%	1	33.3%	0	0.%
	Very	9	47.4%	0	.0%	5	45.5%	2	66.7%	2	66.7%	0	0.%
Vitamin 1	Missing	4	7.0%	2	9.1%	2	12.5%	0	.0%	0	.0%	0	0.%
	Don't Know	7	12.3%	5	22.7%	0	.0%	1	12.5%	1	9.1%	6	23.08%
	Not at all	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Somewhat	22	38.6%	11	50.0%	6	37.5%	4	50.0%	1	9.1%	5	19.23%
	Very	24	42.1%	4	18.2%	8	50.0%	3	37.5%	9	81.8%	15	57.69%
Vitamin 2	Missing	1	5.6%	0	.0%	1	11.1%	0	.0%	0	.0%	0	0.%
	Don't Know	2	11.1%	2	33.3%	0	.0%	0	.0%	0	.0%	2	20.%
	Not at all	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Somewhat	6	33.3%	2	33.3%	3	33.3%	0	.0%	1	33.3%	1	10.%
	Very	9	50.0%	2	33.3%	5	55.6%	0	.0%	2	66.7%	7	70.%
Vitamin 3	Missing	1	12.5%	0	.0%	1	16.7%	0	.0%	0	.0%	0	0.%
	Don't Know	1	12.5%	1	1.0%	0	.0%	0	.0%	0	.0%	?	25.%
	Not at all	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Somewhat	3	37.5%	0	.0%	2	33.3%	0	.0%	1	1.0%	2	50.%
	Very	3	37.5%	0	.0%	3	50.0%	0	.0%	0	.0%	1	25.%
Hom 1	Missing	1	3.8%	0	.0%	1	8.3%	0	.0%	0	.0%	18	78.26%
	Don't Know	1	3.8%	1	16.7%	0	.0%	0	.0%	0	.0%	1	4.35%

	Not at all	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Somewhat	6	23.1%	1	16.7%	1	8.3%	2	66.7%	2	40.0%	1	4.35%
	Very	18	69.2%	4	66.7%	10	83.3%	1	33.3%	3	60.0%	3	13.04%
Hom 2	Missing	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Don't Know	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Not at all	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Somewhat	4	28.6%	0	.0%	2	20.0%	1	1.0%	1	50.0%	1	8.33%
	Very	10	71.4%	1	1.0%	8	80.0%	0	.0%	1	50.0%	11	91.67%
Hom 3	Missing	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Don't Know	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	1	20.%
	Not at all	1	14.3%	0	.0%	0	.0%	1	1.0%	0	.0%	0	0.%
	Somewhat	2	28.6%	0	.0%	2	33.3%	0	.0%	0	.0%	1	20.%
	Very	4	57.1%	0	.0%	4	66.7%	0	.0%	0	.0%	3	60.%
Supp 1	Missing	1	3.8%	1	11.1%	0	.0%	0	.0%	0	.0%	0	0.%
	Don't Know	9	34.6%	5	55.6%	1	20.0%	3	37.5%	0	.0%	0	0.%
	Not at all	0	.0%	0	.0%	0	.0%	0	%	0	.0%	0	0.%
	Somewhat	5	19.2%	1	11.1%	1	20.0%	3	37.5%	0	.0%	1	50.%
	Very	11	42.3%	2	22.2%	3	60.0%	2	25.0%	4	1.0%	1	50.%
Supp 2	Missing	1	25.0%	0	.0%	1	50.0%	0	.0%	0	.0%	0	0.%
	Don't Know	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Not at all	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Somewhat	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Very	3	75.0%	0	.0%	1	50.0%	0	.0%	2	1.0%	0	0.%
Supp 3	Missing	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Don't Know	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Not at all	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Somewhat	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Very	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
Total miss	ing	18	8%	5	10%	12	11%	0	0%	1	3%	20	23%

Table F16. Missing data and helpfulness ratings for each self-care practice

		T	otal		UK	R	omania		Italy		Spain	Neth	nerlands
		n	%	n	%	n	%	n	%	n	%	n	%
Meditation	Missing	2	6.3%	0	.0%	2	33.3%	0	.0%	0	.0%	1	20.%
	Don't Know	2	6.3%	1	11.1%	0	.0%	0	.0%	1	7.7%	0	0.%
	Not at all	1	3.1%	0	.0%	0	.0%	1	25.0%	0	.0%	0	0.%
	Somewhat	7	21.9%	4	44.4%	0	.0%	3	75.0%	0	.0%	1	20.%
	Very	20	62.5%	4	44.4%	4	66.7%	0	.0%	12	92.3%	3	60.%
Yoga	Missing	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Don't Know	1	4.5%	0	.0%	0	.0%	0	.0%	1	□4.3%	0	0.%
	Not at all	1	4.5%	0	.0%	0	.0%	1	16.7%	0	.0%	0	0.%
	Somewhat	6	27.3%	2	28.6%	0	.0%	4	66.7%	0	.0%	0	0.%
	Very	14	63.6%	5	71.4%	2	1.0%	1	16.7%	6	85.7%	5	1.%
Qi Gong	Missing	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Don't Know	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Not at all	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Somewhat	1	14.3%	1	33.3%	0	.0%	0	.0%	0	.0%	0	0.%
	Very	6	85.7%	2	66.7%	0	.0%	0	.0%	4	1.0%	0	0.%
Tai Chi	Missing	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Don't Know	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Not at all	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Somewhat	1	10.0%	1	50.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Very	9	90.0%	1	50.0%	0	.0%	3	1.0%	5	1.0%	1	1.%
Relaxation	Missing	9	19.1%	2	16.7%	4	33.3%	0	.0%	3	17.6%	0	0.%
	Don't Know	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Not at all	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Somewhat	7	14.9%	3	25.0%	2	16.7%	2	33.3%	0	.0%	2	40.%
	Very	31	66.0%	7	58.3%	6	50.0%	4	66.7%	14	82.4%	3	60.%
Visualisation	Missing	3	16.7%	1	11.1%	1	20.0%	0	.0%	1	25.0%	1	50.%
	Don't Know	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Not at all	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Somewhat	3	16.7%	2	22.2%	0	.0%	0	.0%	1	25.0%	0	0.%
	Very	12	66.7%	6	66.7%	4	80.0%	0	.0%	2	50.0%	1	50.%
Traditional	Missing	2	20.0%	0	.0%	2	20.0%	0	.0%	П	.0%	0	0.%

	Not at all	0	.0%	0	.0%	0	.0%	0	.0%	0	.0%	0	0.%
	Somewhat	1	10.0%	0	.0%	1	10.0%	0	.0%	0	.0%	0	0.%
	Very	7	70.0%	0	.0%	7	70.0%	0	.0%	0	.0%	0	0.%
Prayer	Missing	7	10.3%	0	.0%	6	18.2%	0	.0%	1	6.7%	0	0.%
	Don't Know	3	4.4%	1	12.5%	0	.0%	1	8.3%	1	6.7%	0	0.%
	Not at all	1	1.5%	0	.0%	0	.0%	0	.0%	1	6.7%	0	0.%
	Somewhat	13	19.1%	4	50.0%	2	6.1%	5	41.7%	2	13.3%	0	0.%
	Very	44	64.7%	3	37.5%	25	75.8%	6	50.0%	10	66.7%	5	1.%
Total missing		23	11%	3	6%	15	22%	0	0%	5	8%	2	9%