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A Pilot Feasibility Study of a Questionnaire to Determine European Union-Wide CAM Use

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Keywords
Pilot study · Complementary medicine · Prevalence

Summary
Background: No questionnaire specifically measuring the core components of complementary and alternative medicine (CAM) use has been validated for use across European Union (EU) countries. We aimed to determine the face validity, acceptability and the participants' comprehension of a pre-existing questionnaire designed to measure 'CAM use', to provide a comparative, standardised questionnaire for use by health care providers, policy makers and purchasers throughout Europe. **Methods:** Established procedures were employed to translate the questionnaire into 4 EU languages. The translated questionnaires were piloted on 50 healthy adults from each country who may never have used CAM. 10 participants per country also took part in audio-recorded think aloud interviews about the questionnaire. The interviews were transcribed and analysed in the language in which they were conducted; findings were summarised in English. Questionnaire data were pooled across countries, and patterns of completion and missing data were analysed. **Results:** The questionnaire was translated into Italian, Spanish, Dutch and Romanian. The mean age of the participants was 43.6 years. 34% were male, 87.4% were either light or heavy CAM users, and 12.6% were non-users. Qualitative analysis identified common problems across countries including a 'hard-to-read' layout, misunderstood terminology and uncertainty in choosing response options. Quantitative analysis confirmed that a substantial minority of respondents failed to follow questionnaire instructions and that some questions had substantial rates of missing data. **Conclusions:** The I-CAM-Q has low face validity and low acceptability, and is likely to produce biased estimates of CAM use if applied in England, Romania, Italy, The Netherlands or Spain. Further work is required to develop the layout, terms, some response options and instructions for completion before it can be used across the EU.

Schlüsselwörter
Pilotstudie · Komplementärmedizin · Prävalenz

Zusammenfassung
Hintergrund: Bislang wurde noch kein Fragebogen validiert, der ausdrücklich die Kernkomponenten der Anwendung komplementärer und alternativer Medizin (CAM) in der Europäischen Union (EU) erfasst. Unser Ziel war es, die Plausibilität, Akzeptanz und die Verständlichkeit eines bereits bestehenden Fragebogens zu bestimmen, der zur Evaluierung der Anwendung von CAM entwickelt wurde. Damit versuchen wir, einen vergleichenden, standardisierten Fragebogen zur Verfügung zu stellen, der von Dienstleistern im Gesundheitswesen, politischen Entscheidungsträgern und Anwendern in Europa genutzt werden kann. **Methoden:** Der Fragebogen wurde mittels etablierter Verfahren in 4 europäische Sprachen übersetzt. Die übersetzten Fragebögen wurden 50 gesunden Erwachsenen aus jedem europäischen Land vorgelegt, die CAM möglichweise noch nie genutzt haben. 10 Teilnehmer pro Land haben sich des Weiteren einem «laut gedachten» Interview zum Fragebogen unterzogen. Die Interviews wurden transkribiert und in der Sprache ausgewertet, in der sie geführt wurden. Die Ergebnisse wurden in englischer Sprache zusammengefasst. Die erhobenen Fragebogen-Daten wurden zusammengefasst und die Antwortmuster sowie fehlende Angaben ausgewertet. **Ergebnisse:** Der Fragebogen wurde ins Italienische, Spanische, Niederländische und Rumänische übersetzt. Das Durchschnittsalter der Teilnehmer war 43,6 Jahre. 34% der Teilnehmer waren männlich, 87,4% nutzten CAM selten bis häufig, 12,6% wandten CAM nicht an. Die qualitative Auswertung ergab Überschneidungen unter den Teilnehmern aus den verschiedenen Ländern bezüglich der Schwierigkeiten in der Lesbarkeit des Layouts, Missverständlichkeit der Begriffe und Unsicherheit in der Auswahl von Antwortmöglichkeiten. Zudem bestätigte die Analyse, dass eine nicht unerhebliche Minderheit der Teilnehmer den Anleitungen im Fragebogen nicht folgen konnte und dass einige Fragen große Datenlücken auswiesen. **Schlussfolgerungen:** Der internationale Fragebogen zur Erfassung der Anwendung von CAM (I-CAM-Q) zeigt eine geringe Plausibilität sowie Akzeptanz und lässt verzerrte Schätzungen der Anwendung von CAM vermuten, insofern er in England, Rumänien und Italien, den Niederlanden oder Spanien zum Einsatz kommt. Weitere Forschung ist notwendig, um Layout, Begriffe, einige der Antwortmöglichkeiten und Anleitungen für die Bearbeitung weiterzuentwickeln, bevor der Fragebogen europaweit Anwendung finden wird.

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Introduction

The use of complementary and alternative medicine (CAM) has increased considerably in recent years [1–5], but it is difficult to reliably compare prevalence across European Union (EU) member states due to differing definitions of CAM, varying response time frames over which CAM use is measured and differing disease-versus-general population samples [6]. It is important that we develop a reliable method of measuring CAM prevalence to provide information allowing us to address issues such as EU health planning and citizens' needs.

The International Questionnaire to measure use of Complementary and Alternative Medicine (I-CAM-Q) [7] constitutes a good candidate for an international standard measure of CAM use. The questionnaire aims to be usable in different languages and populations, by having a number of core items to be used on all versions of the questionnaire and the option to add extra items on local versions if necessary to assess the most common forms in CAM in a particular context.

The I-CAM-Q has been used in several peer-reviewed published studies [8–11]. To date, no psychometric or other field tests of the I-CAM-Q have been published. While it is undoubtedly important to understand a questionnaire's formal measurement properties (reliability and validity), a useful preliminary step is to ensure that item wording and instrument design maximise the potential to collect accurate data. When people respond to questionnaire items, they are engaging in a complex cognitive task, which has been characterised as involving comprehension, retrieval, judgement and response processes [8]. Think aloud methods can provide a window onto these processes [9] and enable researchers to improve data accuracy by modifying item wording, framing and response options [12].

Therefore, we conducted a pilot study incorporating think aloud methods to understand the basic properties of the I-CAM-Q in a normal healthy adult population who may never have used CAM. We wished to ascertain how adults understood and evaluated the face validity of the questionnaire. The aims of this study were to evaluate the acceptability of the I-CAM-Q from the participants' perspective and their ability to understand and effectively respond to the questions posed. We also wished to investigate the feasibility of using a self-complete delivery mechanism to measure CAM prevalence across the EU. The study size planned for this pilot is not adequate to allow detailed analysis of non-responders or to allow us to draw any conclusions about CAM users in the population. We did not plan or power this study to allow us to examine the detailed psychometrics of this questionnaire. The specific objectives were to translate the questionnaire into at least 3 European languages, to generate preliminary evidence concerning the face validity, acceptability and basic characteristics of the I-CAM-Q across different populations (including individuals who had and had not used CAM) and to identify any ways in which the questionnaire wording or layout could be improved if necessary.

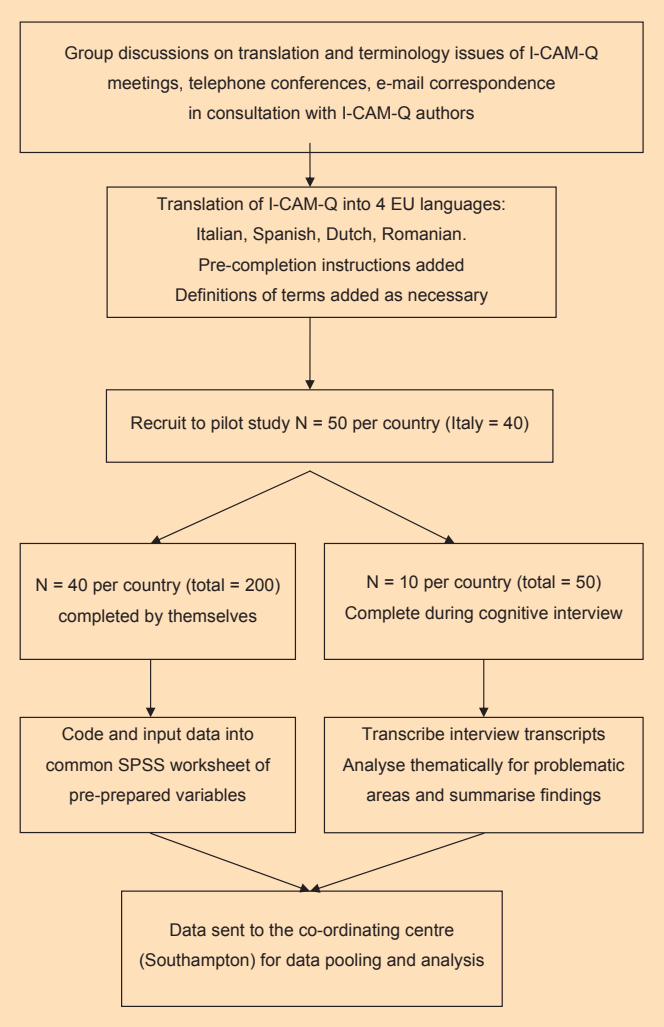

Fig. 1. Flow chart of the study protocol.

Methods

Design

This was a cross-sectional multi-centre pilot study in which all participants completed the I-CAM-Q once (in their country's language), and a sub-sample also took part in 'think aloud' cognitive interviews (fig. 1).

Ethical approval was obtained as necessary in each country (UK Ethics No. SOMSEC093.10).

The Questionnaire

The I-CAM-Q comprises 4 main questions: Question 1: Visiting health care providers. Question 2: Complementary treatments received from physicians (MDs). Question 3: Use of herbal medicine and dietary supplements. Question 4: Self-help practices. For each main question there are a number of sub-questions: Respondents are asked to indicate whether or not they used a particular provider / health care practice/product, the number of times they used the service in a given time period, their main reason for use and helpfulness of the practice/product.

Table 1. Demographic characteristics of the study participants by country[a]

	Total	UK	Romania	Italy	Spain
Number of participants	190	50	50	40	50
Age, years, mean (SD)	43.60 (16.02)	41.32 (18.60)	47.22 (12.26)	37.40 (12.26)	47.2 (12.93)
Gender, n (%)					
Man	64 (34%)	21 (42%)	23 (46%)	0 (0%)	20 (40%)
Woman	126 (66%)	29 (58%)	27 (54%)	40 (100%)	30 (60%)
Birth country, n (%)					
UK	43 (23%)	43 (86%)	0 (0%)	0 (0%)	0 (0%)
The 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 (98%)	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, n (%)					
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, n (%)					
Yes	32 (17%)	10 (20%)	5 (10%)	0 (0%)	17 (34%)
Missing	2 (1%)	1 (2%)	0 (0%)	0 (0%)	1 (2%)
Highest education level, n (%)					
O level / CSE	11 (6%)	5 (10%)	4 (8%)	0 (0%)	2 (4%)
A level	28 (15%)	5 (10%)	7 (14%)	7 (18%)	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 (3%)	12 (24%)
Missing	2 (1%)	2 (4%)	0 (0%)	0 (0%)	0 (0%)
General health status, n (%)					
Excellent	18 (9%)	9 (18%)	4 (8%)	1 (2.5%)	4 (9%)
Very good	70 (37%)	32 (64%)	18 (36%)	3 (8%)	17 (34%)
Good	65 (34%)	8 (16%)	14 (28%)	21 (53%)	22 (44%)
Fair	34 (18%)	1 (2%)	14 (28%)	13 (33%)	6 (12%)
Poor	3 (2%)	0 (0%)	0 (0%)	2 (5%)	1 (2%)
Chronic illness, n (%)					
Yes	59 (31%)	16 (32%)	20 (40%)	14 (35%)	9 (18%)
Missing	3 (2%)	2 (4%)	0 (0%)	0 (0%)	1 (2%)
CAM use, n (%)					
Non-users	24 (13%)	7 (14%)	4 (8%)	9 (23%)	4 (8%)
Light users (1–2 modalities)	66 (35%)	22 (44%)	8 (16%)	17 (54%)	19 (38%)
Heavy users (>2 modalities)	100 (53%)	21 (42%)	38 (76%)	14 (35%)	27 (54%)

[a]No demographic data was available from The Netherlands.
Percentages have been rounded to the nearest whole number and may not always amount to 100%.
CSE = Certificate of secondary education.

Translation of the questionnaire into EU languages following the European Organisation for Research and Treatment of Cancer (EORTC) procedure (translation into the target langue from the original questionnaire language and retranslation back to the original language) [13] was completed by March 2011. Difficult terms and issues from each country were discussed in consultation with the I-CAM-Q authors. Items were translated to overcome local variation and misunderstanding in therapies across countries; e.g., 'herbs' was translated as 'medicinal plants' in Spanish, 'chiropractic' as 'manual therapy' in Romania. 'Spiritual healing' (assumed different from church healing by the developers) was the most contentions term considered a religious matter in some EU countries; therefore, where necessary, respondents were given written definitions. Definitions were added for some countries where the researchers thought particular terms would be poorly understood (e.g., spiritual healing). Instructions for completion were added for all countries.

An additional questionnaire designed for this pilot study included open-ended questions assessing the acceptability of the I-CAM-Q and standard questions assessing socio-demographic characteristics and health status.

Participants

Centres in the UK, Spain, Italy, The Netherlands and Romania recruited 50 respondents to complete the I-CAM-Q (10 from each centre receiving a cognitive interview) to assess face validity, acceptability, rates of missing data and compliance with instructions. Inclusion criteria were: adult (≥16 years), capable of giving informed consent. Recruitment was carried out in our places of work and among the investigators' 'social networks'. A purposive sample was recruited to include heavy, light and never CAM users with average or below-average reading ability, with and without a

chronic illness. As shown in table 1, we broadly achieved our aims of including participants with a range of health, education and CAM experiences; however, a high proportion of respondents across countries reported good or very good self-rated health status and higher levels of education and were light or heavy CAM users. No demographic data was available from The Netherlands. Prevalence rates of CAM use are only presented in table 1 to describe our sample characteristics and should not be used as an estimate of CAM prevalence in the EU.

Procedure

Self-complete respondents completed and returned paper copies of the questionnaires by hand or post. Completion and return of the questionnaire was sufficient to indicate consent. In The Netherlands, the questionnaires were completed online, which differed from the self-complete version piloted by the other centres in that the researchers had greater control over how respondents used the questionnaire: Question routing was automatically controlled and only completed questionnaires were allowed to be submitted. The data from The Netherlands were therefore not included in the quantitative data analysis, but we did include the think aloud data from The Netherlands in the qualitative analysis.

Cognitive interview (think aloud) respondents gave their written informed consent and completed the questionnaires in the presence of an interviewer. The study was explained and a warm-up exercise was used to accustom participants to the requirement to speak their thoughts out loud. Respondents were then asked to verbalise their thoughts as they first saw and then completed the I-CAM-Q. The interviewer asked additional probing questions to further elicit the respondents' understanding of and reaction to the I-CAM-Q. Cognitive interviews were audio-recorded and transcribed.

Data Analysis

Qualitative – Interview Data

Each centre transcribed their cognitive interviews and read the transcripts repeatedly. Any misunderstandings or difficulties that respondents experienced when completing the I-CAM-Q were identified, and similar comments were grouped together to form categories. These categories were summarised, and possible solutions were suggested that could help improve the I-CAM-Q. The centres summarised their findings in English for collation by Southampton. The collated findings were circulated to all centres to ensure that 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.

Quantitative – Questionnaire Data

Participating countries coded their data according to the co-ordinating centre guidelines, inputting to a pre-prepared SPSS spread sheet containing the required variables. Blanks were coded to distinguish between items appropriately left blank (e.g., respondents reporting no use of a modality were not required to report any further details about that modality) and missing data, defined as items that should have been completed but were not (e.g., when respondents reported using a modality but failed to report the required further details like frequency of 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. Data from each participating country were collated into a single data file in SPSS version 19 in Southampton.

Basic descriptive statistics for the entire sample and for each country separately were produced to describe the respondents' characteristics and responses to each item on the I-CAM-Q. Quantitative analysis focused on the extent to which respondents followed the instructions on the I-CAM-Q and the extent of missing data. 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.

Box 1.

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

Results

Copies of the translated questionnaires may be found in the full report along with all other additional materials including country interview summaries, ethical approval documentation, translated copies of the questionnaire, specific instructions for every country and tables of results from the quantitative data analysis (available at *http://content.karger.com/ProdukteDB/produkte.asp?doi=345839*).

Qualitative Findings

We identified 6 main areas of the questionnaire that participants found difficult and which could thus be revised to improve the questionnaire in future: terminology (names of practices), categories (e.g., herbal or homoeopathic), reasons for use, 'other' options (other practices not specifically listed), layout and formatting and response options (recall – remembering how many visits to practitioners).

Terminology

Respondents in each country did not know the meaning of some of the terms (names of practices). Box 1 contains terms that were problematic, summarised by a quote from a UK interviewee:

'… that I'm not familiar with (the terms), cause I didn't know what they were.'

In the UK, 9 participants were unfamiliar with the term 'physician' (I-CAM-Q, Question 1).

In UK, Spain and Italy, some respondents did not recognise the term or could not differentiate between homeopathy/homeopath, herbs/herbalist and acupuncture. Chiropractic and manipulation was similarly misunderstood in the UK and Spain as was spiritual healing in Italy and Spain:

'… 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 …'

Homeopathic or herbal remedy users in The Netherlands, the UK and Romania did not know whether their remedy was homeopathic or herbal or its name:

'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 …'

Respondents who took more dietary supplements than there were spaces to record them (The Netherlands, UK, Italy, Romania) were confused about which to report.

Respondents across countries were unable to rate the helpfulness of some products they took (herbal remedies, dietary supplements) or some self-help practices they used (Yoga, meditation) because they used them as a preventative measure. Qigong proved the most problematic self-help practice, with few people in any country recognising the term:

' … 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 …'

Categories

A number of participants suggested that some terms were too broad or ambiguous and categories were not clearly specified. Even the overarching category 'complementary medicine' was not understood by some respondents in the UK, The Netherlands and Spain.

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

Reasons for Use

When respondents reported using a practice, they were required to indicate their main reason for using it from 4 possible options. Respondents were unclear about the difference between 2 of the options, in particular, when choosing whether they used a practice for an acute illness or for a long-standing health problem. Respondents were often unsure whether a particular condition constituted an acute or a long-term problem, whether it was sufficiently serious or whether a complaint was an 'illness' at all (e.g., slipped disc). Respondents often ticked more than one reason for visiting a practitioner because they went for several reasons and could not choose between them.

Options

The last sub-sections of each question, entitled 'specified' and 'other option', allowed respondents to write in a practice they used that was not already listed elsewhere. Participants found these options confusing:

'Though what's this with specified option and other option, other please specify. What are the 2 different things?'

Layout and Formatting

A number of participants deemed the questionnaire layout 'unclear', 'muddly' and having 'quite a lot on the page'. Respondents in the UK, Spain, Romania and The Netherlands frequently missed completing sections because they did not see something they ought to have completed:

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

Across countries, interviewers reported that respondents did not read the questionnaire properly: Respondents carried on ticking down the page for the first column where they reported use of a practice, thus missing the subsequent related questions about the number of consultations, reasons for use, and satisfaction with use. The vertical writing in columns at the top of each page proved highly unpopular; participants across all countries complained that it made the questionnaire hard to read:

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

Respondents talked about Questions 1 and 2 as being very similar and thus confusing. This suggests that people did not understand or remember or recognise the distinction between practitioners with and without bio-medical qualifications (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).

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

Recall

Respondents found it confusing and difficult to have to recall whether they had used a modality in the last 12 months and then switch to recalling how many times they had used it in the last 3 months (Romania, UK, The Netherlands). People from each country could not remember how many times they had seen a practitioner at all. 1 person summed up this problem by saying:

'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 …'

Respondents in the UK and Italy were concerned how to record their answers if they did not use a practice. For example in Question 3 asking about the use of dietary supplements, people did not know if they could leave the question blank if they did not take a supplement or if they had to tick 'no' for each option. In the UK, several people commented that they did not know how to indicate their responses on the form, i.e., whether to put a cross in each box (because computer surveys use a cross) or a tick; respondents in Italy were also unsure about this.

In rating the helpfulness of an intervention (very, somewhat or not at all helpful) 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.

Quantitative Data Analysis

In the quantitative analysis, we focused on the extent to which the questionnaires were incorrectly or incompletely filled out.

Table 2. Summary of missing data across the 4 main I-CAM-Q questions

Question stem	Question		Missing data	
	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[a]	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

Number and percentage of missing data is calculated as a total across all individual items within each question.
[a]'Missing' total includes multiple responses as well as missing responses.
NA = Not applicable.

Overview of Missing Data across Questions

The questions that 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.) (table 2). When CAM modalities were used, participants often failed to report the frequency of use: Question 1 (frequency of use of health care provider-delivered CAM) demonstrated overall 30% missing data, with more than 10% missing for each country; Question 2 (frequency of use of physician-delivered CAM) demonstrated 29% missing data overall, with more than 10% per country); and Question 4 (frequency of use of self-help practices) demonstrated 50% missing data overall and more than 50% missing per country. Question 3 does not ask about frequency of use. For all types of CAM modality, approximately one third of the respondents failed to report their main single reason for use (more than 10% per country). The question concerning the respondents' perceptions of the helpfulness of each CAM was also left unanswered 1 time in 10.

Compliance with Instructions about Question Routing

According to the I-CAM-Q instructions, only respondents who reported having seen a physician in the past 12 months (on Question 1) should have completed Question 2. On average, two thirds of the 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.

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. Rates of incorrect responses were substantial for all the different language versions of the I-CAM-Q, typically above 10% for each question.

Discussion

Summary

The results of the study indicate low face validity and acceptability of the I-CAM-Q across 5 EU countries. Cognitive interviews identified areas for improvement including questionnaire layout, terminology and response options. Quantitative analysis reported substantial missing data or incorrect response options. The samples involved for each country are

small and therefore these quantitive results must be interpreted with caution. While self-completed questionnaires often experience missing data, to ensure that results can be generalised we would want missing data to be both infrequent (<5%) and missing at random (not be related to the outcome variable) [14]. The extent of missing data taken in conjunction with the information from the think aloud interviews suggest essential further development work to ensure the validity and reliability of the I-CAM-Q if it is to be used in future studies.

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 that it would be better to modify or explain problematic terminology for respondents. The questionnaire does not allow for a 'don't know' option and this may be a valuable inclusion. Different sampling methods may also have introduced some basis (the Dutch questionnaire was completed online) and we would need a larger study to ascertain if this introduced bias.

Despite homeopathy, herbal medicine and acupuncture being arguably the most prevalent CAMs, these terms were often misunderstood. Across all countries, Question 4 (self-help techniques) caused confusion as people did not know what they were or generally thought they were preventative measures rather than treatments. Respondents were therefore unable to rate their helpfulness, as demonstrated by high levels of missing data. If large sectors of the population see self-help techniques as preventative measures, then the wording of Question 4 is currently not measuring how the population understands the construct. This was also true for Question 3 (use of vitamins and natural remedies). Where the helpfulness sections had been completed, there is a potential for answers to be constrained by the response options, limiting the accuracy of the data: Some respondents complained that an extra category between 'somewhat' and 'very helpful' was needed.

Respondents did not understand some of the categories and suggested that they may be too broad and open to misinterpretation. Even the category 'complementary medicine' was misunderstood. People may not have understood if their CAM practitioner was 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 seen their doctor. If the respondents do not appreciate that their CAM practitioner is a doctor then they may complete Question 2 when they should not or complete Question 1 incorrectly. On average, two thirds of the respondents completed Question 2 when they should not, as well as not reading the questionnaire properly.

There were large amounts of incorrect responses and missing data across all countries in the 'reasons for use' sections. Overall, approximately 30% of the respondents answered incorrectly for all 4 questions. Interviewers from all countries reported that respondents were not reading the questionnaire properly and therefore not completing all the sections; it is quite possible that people consult a practitioner for more than one reason, hence ticking several options. Qualitative and survey research suggests that people use CAM for multiple reasons [15–18]. Forcing people to select a single reason is therefore likely to be an over-simplification that risks producing an inaccurate understanding of CAM use.

There was confusion across countries in relation to the definition of a chronic or acute illness, suggesting that these medical terms are not well understood and more familiar, 'lay' terminology might be more appropriate.

Respondents from all countries found the questionnaire hard to read and understand. Of particular significance was the use of vertical 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. These data suggests that the acceptability of the I-CAM-Q to the study population is poor.

During interviews, respondents frequently reported that they could not remember how many times they had seen a practitioner, and some of them simply said they were guessing, indicating that the data could be subject to recall bias. Our quantitative data on the frequency of visits revealed that more than 10% of data was missing for each country for each relevant question; this is a substantial limitation and further questionnaire development would be necessary to present response options that respondents find acceptable while minimising recall bias. Opinion varies as to the appropriate timescale for questions such as these [19]. 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 [19].

Recommendations

The I-CAM-Q could be used as a self-report measure to survey CAM use in the European population, and it was possible to create commensurate translations of the questionnaire for use in different countries. However, before using the I-CAM-Q in any major survey, we recommend several developmental modifications (table 3). Administering the questionnaire in person or online might also alleviate some of the problems we identified.

Strengths and Limitations (of Our Pilot)

We achieved our research aims in recruiting members of the population across countries from differing health, education and CAM use categories and recruited the sample size

Table 3. Suggested modifications to the I-CAM-Q

No.	Suggested modification
1	Revise the layout so that all the writing reads horizontally.
2	Use terms and definitions that are relevant to the country in which it will be administered. Make sure that UK, Canadian, US and Australian versions of the questionnaire are adequately piloted in that country before use.
3	Do not systematically separate out physician-delivered CAM from other forms of practitioner-based CAM. Instead, present a single list of all core practitioner-based CAM modalities.
4	Revise the 'frequency of use' items. These items should either be removed, the recall period reduced, or fixed options provided.
5	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.
6	Remove questions about helpfulness or change the response scale to allow more nuanced responses while retaining a 'not sure' option.
7	Find a shared and translatable definition for some modalities (e.g., spiritual healing) and remove some of the lesser-known modalities (e.g., Qigong).
8	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.
9	Add a definition of CAM and an explanation that participants should use the 'other' options to name additional CAM modalities that they have used.
10	Increase the acceptability, face validity and accessibility of the questionnaire for non-CAM users (if we wish to evaluate the prevalence of CAM) by adding items about the use of conventional health services or by more clearly sign-posting a route through the questionnaire for non-users.

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 across countries.

The data are limited in that we did not recruit many participants with poor self-rated health and lower education status and, therefore, we may not have discovered issues in the questionnaire for these population sectors. We only piloted the questionnaire in 5 EU countries (UK, The Netherlands, Spain, Romania and Italy) although we suspected that respondents in other countries would have given us similar data, given the relative consistency of the results. As with any self-report study, it is possible that participants in the cognitive interviews did not speak aloud or voice all of their relevant thoughts when completing the I-CAM-Q.

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 the layout of the questionnaire difficult to read and understand and that the questionnaires were completed incorrectly. 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, casting doubt on the accuracy of any data collected. Our reason for initiating this study was to achieve an understanding of the core data required to measure CAM use across the EU. The I-CAM-Q is not currently fit for this purpose, but we now have a much clearer idea of the issues that need to be addressed in its development.

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