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## Preface

The present report comprises the description of objectives, methodology and findings of Work Package 3 on “Needs and attitudes of citizens” concerning complementary and alternative medicine (CAM) in Europe. This topic is of special interest within the overall composition of CAMbrella’s work packages since it addresses a very important group of stakeholders in a sound health care system. With only few exceptions every citizen in European countries has come into contact with the health system as a former patient, is currently under treatment or will probably become a patient in the future. One part of this health system is covered by CAM, and the principal task of Work Package 3 was to elaborate which kind of needs and attitudes related to this specific field of medicine can be attributed to the people living in the different areas of the EU. Such a difficult undertaking is necessarily connected with particular challenges, some of which should be noted upfront:

- The main challenge when exploring CAM is the lack of a shared understanding of the term ‘CAM’. Although the CAMbrella project is trying to overcome this issue by a separate work package, new concepts and recommendations for the future use of terminology in the area of CAM have no impact on its use in already existing literature. When exploring the current status of CAM within the CAMbrella project this process should not be limited by a too narrow use of the term ‘CAM’. The underlying working definition is best characterized as: ‘Complementary and alternative medicine is a group of diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine’ (NCCAM<sup>1</sup>). In reviewing the existing literature every effort has been made to use the term CAM as used by the authors of the identified articles.
- CAMbrella includes: all full EU member states, countries belonging to the EFTA, selected Candidate countries, and selected countries associated with FP7.
- When conducting a systematic review of literature with respect to a given topic some limitations are inevitable regarding choice of databases, the focus of the search, the articles’ language or the search terms used in connection with the underlying literature databases. All these criteria have impact on the final results of the literature search.
- It should also be pointed out that it proved difficult to cover all European countries adequately. Possibly more articles dealing with citizens’ needs and attitudes are published in journals of the respective mother language. It therefore is important to emphasise that literature sources may exist which are not reflected in this report.

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<sup>1</sup> <http://nccam.nih.gov/health/whatiscam/#definingcam>

This does not mean that these publications are of minor relevance and thus ignored for whatever reason, but are excluded merely due to the inclusion or exclusion criteria used for the review of literature presented in this report. Restricting to English language articles or articles with an English abstract may therefore have resulted in an incomplete representation of knowledge about CAM in European countries.

- The findings of Work Package 1 on terminology and Work Package 2 on the legal status of CAM revealed a very heterogeneous picture for Europe. Both approaches are closely interrelated with and impact on the understanding of CAM in the different countries, and this has to be taken into account for the appraisal of the present findings of Work Package 3.
- The topic of the present report cannot be considered independently from other CAMbrella work packages, especially from Work Package 4 which explores the extent of use of CAM interventions and identifies the reasons for seeking this kind of treatment, or Work Package 5 which focuses on the perspective of CAM providers. Although these work packages focus on medical reasons a certain overlap with Work Package 3 has to be assumed concerning citizens' more general motives, beliefs, needs and attitudes to CAM. The investigations of the various work packages were carried out more or less side by side and their findings will feed into a common strategic roadmap for future research in the field of CAM (see Work Package 7).

Wolfgang Weidenhammer

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## Executive Summary

This report describes the work and findings of Work Package 3 (WP3) of CAMbrella, a pan-European research network for complementary and alternative medicine (CAM). The aim of WP3 was to collect information on citizens' attitudes and needs in EU member states and selected associated countries.

### *Methodology*

Two main complementary methods were used to achieve this aim: a workshop with stakeholders knowledgeable about citizens' attitudes and needs concerning CAM, and a review of literature.

A purposeful sample of stakeholders was invited for a workshop. The workshop aimed to identify how to explore citizens' attitudes and needs concerning CAM; facilitate the sharing of relevant information; and help to identify how citizens' attitudes and needs concerning CAM can be measured and compared across the many EU countries. The participants emphasised the interrelationship between citizens' attitudes to CAM and their needs, and identified key issues relating to citizens' needs. The outcomes of the workshop provided the basis for developing indicators for citizens' needs concerning CAM and informed the subsequent review of literature which explores citizens' attitudes and needs regarding CAM.

For the review of literature of citizens' attitudes and needs concerning CAM, WP3 developed a comprehensive literature search strategy. The resulting searches of international academic databases identified 189 articles which constitute the basis for the findings presented in this report. The geographical distribution of articles highlights a dominance of UK based articles (78 articles), a range of countries with between 9 and 30 articles per country, and a significant number of countries where the literature searches provided few or no articles. This means that in this report not all the EU countries could be explored in equal depth and some countries are not covered at all. A majority of identified articles examines citizens' attitudes and needs as part of other research interests in the field of CAM, and only few address research questions of direct relevance to the focus of WP3. This highlights that citizens' attitudes and needs concerning CAM constitute a considerably under-studied area of research.

Three main themes emerged from the stakeholder workshop and the analysis of the articles identified through the literature searches. These are:

- Information about CAM
- Access to CAM
- Quality of care in CAM

### *Key findings*

Although the UK is over-represented in the literature reviewed in this report and the reporting quality of many articles is variable, the following general trends in relation to citizens' attitudes and needs concerning CAM can be noted:

- A majority of citizens holds positive attitudes to CAM, and demand and support increased and diverse CAM provision in public health services.
- Citizens' attitudes and needs concerning CAM are shown to be embedded in a multi-dimensional decision-making environment which encompasses many diverse issues relating to the availability of information about CAM, access to CAM provision, and the quality and safety of CAM practice and CAM medicinal products.
- A link between the availability of information about CAM and citizens' non-use of CAM is noted in the literature. This highlights the need for accessible, reliable and trustworthy information about CAM to enable citizens to make informed choices about their healthcare.
- Citizens gather information about CAM in two main ways. In some countries (e.g. the UK, Turkey, Israel, Norway and Ireland) citizens' social networks constitute the main source of information about CAM. In these countries, biomedical professionals as information source are relatively less important, though some citizens indicate that they would like to receive information about CAM through this channel. By contrast, in countries where CAM is frequently provided by biomedical professionals (e.g. Germany) these professionals often constitute a key source of information, with information shared through social networks tending to be relatively less important. In addition, citizens also particularly draw on print and broadcast media to gather information.
- Citizens' demand for increasing availability of CAM in public health services links with their diverse needs when seeking to access CAM provision, such as the barriers to CAM use they experience and/or perceive (e.g. the financial cost of CAM, biomedical professionals' negative attitudes to CAM), and their wish for a more active role of biomedical professionals in supporting their CAM use.
- Citizens' attitudes and needs concerning the quality of care in CAM highlight that they value distinct aspects of CAM practice, including the CAM provider-patient relationship; a whole person approach frequently associated with the practice of CAM; and explanatory frameworks that are often congruent with citizens own ideas about health and illness. Despite this appreciation of CAM, citizens are also critical of CAM practice.
- In assessing the safety and quality of CAM provision, citizens frequently draw on their own or others' personal experiences with CAM. They also stress the importance of transparency concerning CAM qualifications, and emphasise the need for increased and clear regulation and registration of all CAM providers. In addition, some citizens would like to be guided by biomedical professionals. Thus, although citizens' assessment of the safety and quality of CAM may differ from such

assessments by biomedical professionals, citizens are forming their own considered judgment about what is an acceptable level of risk concerning their use of CAM.

*Future research of citizens' attitudes and needs concerning CAM*

A rich research agenda arises from the work of WP3, including the following recommendations:

- To address methodological issues when examining citizens' attitudes and needs concerning CAM
- To develop comparable and compatible research of citizens' attitudes and needs concerning CAM in the complete range of EU countries
- To investigate the implications of citizens' diversity (e.g. in terms of age, gender, ethnicity, social class) and the diversity of CAM in explorations of citizens' attitudes and needs concerning CAM

With these issues in mind, further detailed suggestions are made for research into citizens' attitudes and needs in Europe, with particular attention to information about CAM; access to CAM, and the quality of care in CAM.

'Horizon 2020', the recent proposal for a European framework programme of research with a focus on 'Health, demographic change, and wellbeing' is suggested as a possible basis for further research into CAM, including citizens' attitudes and needs.

The developments arising from both the work of WP3 and the up-and-coming research priorities in Europe will be taken forward by CAMbrella WP7. The task of WP7 is to consider the conclusions and recommendations of all CAMbrella Work Packages. In so doing, CAMbrella will conclude its work with coordinated suggestions for a strategic research agenda and a roadmap for future CAM research in Europe.

## 1 Introduction

This section sets out the WP3 aim and objectives, together with the main tasks that frame and underpin the work of WP3 and the ways in which WP3 partners understand and use key terms that shape its work. This is followed by a sketch of the EU health policy context within which CAMbrella and the work of WP3 is situated.

### 1.1 Defining the problem: WP3 aim, objectives and tasks

#### 1.1.1 WP3 aim and objectives

The aim of WP3 is to collect information on citizens' needs and attitudes to CAM in EU member states and a selection of associated countries. The following four objectives guide this work:

1. To identify cross-European indicators for population-based needs and attitudes regarding CAM
2. To identify and map the needs of European citizens with respect to CAM
3. To identify and map EU citizens' attitudes towards CAM
4. To provide information on citizens' needs and attitudes regarding CAM

#### 1.1.2 WP3 tasks

To achieve the above aim and objectives, four main tasks frame the work of WP3:

1. Identify stakeholders and indicators for needs
  - a. To identify relevant stakeholders (e.g. national consumer councils, relevant patient organisations, national boards of CAM, etc.) regarding citizens' needs and attitudes
  - b. Workshop with a selection of relevant stakeholders with the aim of: (i) Identifying relevant indicators for citizens' needs regarding information, regulation, quality and safety control, etc., (ii) Identifying relevant sources of information in the participating countries
2. Establish an overview of the needs
  - a. Establish a procedure for information collection regarding citizens' needs in the participating countries
  - b. Cross-European collection of information concerning the needs of EU citizens (with special emphasis on children and elderly persons) from the available literature and subsequently mapping their apparent information requirements for the future concerning areas such as effectiveness, regulation, quality and safety

3. Establish an overview of attitudes towards CAM
  - a. Establish a procedure for information collection regarding citizens' attitudes in the participating countries
  - b. Cross-European collection of published information on the attitudes of citizens regarding CAM and the provision of CAM
4. Write a report on citizens' needs and attitudes
  - a. Results from tasks 3.1 - 3.3 will be reported in writing for the information of WP7.
  - b. The report will be available for the European public and relevant stakeholders on pertinent internet sites, e.g. the CAMbrella website ([www.cambrella.eu](http://www.cambrella.eu)).

The above tasks shape the work of WP3 and were operationalised in the following ways:

- Task 1:
  - WP3 identified a purposeful sample of stakeholders (Task 1a). These stakeholders were invited and attended the Stakeholder Workshop (Task 1b)
  - Key outcomes from the Stakeholder Workshop provided the basis for the development of relevant indicators for citizens' needs (Task 1b) and were subsequently integrated into Tasks 2 and 3
  - Following the workshop in Vienna, a questionnaire was sent to national CAMbrella representatives and the workshop participants in order to identify relevant sources of information across the EU countries (Tasks 1b)
- Tasks 2 and 3:
  - WP3 initiated and carried out a review of literature concerning EU citizens' attitudes and needs concerning CAM
- Task 4:
  - The results of Tasks 1-3 are presented in this report.

In reporting on these tasks, the structure of this report broadly follows the order of the tasks, as listed above.

### 1.1.3 WP3 terminology

An early undertaking for WP3 was the development of a shared understanding of the three key terms - 'citizen', 'attitude' and 'need' - that shape the work of WP3. With input from stakeholders (see below) the following working definitions of these terms were adopted:

- *Citizen*: any individual, irrespective of whether or not they have used CAM modalities in the past, may use them in the future or are current users

This understanding of the term ‘citizen’ draws attention to individuals as members of civil society and recognises the differences that exist for different citizens and/or groups of citizens, e.g. in terms of availability and access to CAM provision and products, legal restrictions on the CAM treatment of children, and individuals’ abilities to make choices concerning their healthcare.

- *Attitude*: a disposition or state of being for or against something that is associated with emotions, feelings and values.

Attitudes are said to influence behaviour and actions e.g. in health and of consumers. In turn, attitudes are also influenced and shaped by wider social, cultural, political and economic contexts.

- *Need*: the starting point for the consideration of health needs is the WHO understanding of health as a human right; that is, *"the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being..."* (WHO constitution)

In the context of health as a human right, two key perspectives on CAM can be identified: the citizens’ perspective and the governance perspective. These two perspectives may at times complement each other, overlap or be contested. The work of WP3 focuses on the citizens’ perspective.

In addition, with reference to the term CAM WP3 has adopted the following: in reporting on the literature about citizens’ attitudes and needs concerning CAM we endeavoured to use, where possible, the terms and understandings of CAM used by the author/s of the identified articles. Otherwise, we draw on the working definition of CAM set out in the ‘preface’ above.<sup>2</sup>

## 1.2 The EU health policy context

The EU health policy context provides the wider context within which the work of CAMbrella WP3 takes place and the framework within which EU citizens’ rights, obligations of healthcare providers towards patients, and citizens’ attitudes and needs concerning healthcare, including CAM, are situated. To this end, this section sketches the EU health policy context, together with EU health research policy as it relates to CAM.

The EU health policy environment is underpinned by a commitment to citizen engagement and a patient-centred approach to addressing health issues across the EU.<sup>3</sup> The Programme of Community Action in the field of Health and Consumer protection 2007-2013, entitled

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<sup>2</sup> For further details about the diversity of CAM definitions, see CAMbrella Work Package 1 which identified a great heterogeneity of definitions and understandings of CAM, both within Europe and internationally.

<sup>3</sup> [http://ec.europa.eu/dgs/health\\_consumer/consumervoice/cv\\_62010\\_en.pdf](http://ec.europa.eu/dgs/health_consumer/consumervoice/cv_62010_en.pdf)

'*Healthier, safer, more confident citizens: A health and consumer protection strategy*'<sup>4</sup> for example acknowledges that EU citizens not only want to live 'healthily and safely wherever and wherever they are and to have confidence in the products and services they consume. They also want a say in the decisions that affect their health and their consumer interests (p2)'. Accordingly, one central objective across the EU is to increase the ability of citizens to make better decisions about their health and consumer interests (ibid, p3). To this end, health information and knowledge is generated and disseminated so that citizens can share responsibility for improving their health<sup>5,6</sup>. Complementing this objective is a European health information strategy<sup>7</sup> which aims to provide information and analysis of evidence-based developments, implementation and evaluation of action for health at both EU community level and within EU member states.

Alongside this focus on citizens' multi-faceted involvement in health, a set of common values and principles underpin EU health systems which aim to make provision patient-centred and responsive to individual need.<sup>8</sup> The overarching values focus on: universality; access to good quality care; equity; and solidarity. Universality means that everyone has access to healthcare; solidarity is closely related to the financial arrangements of public healthcare systems and the need to ensure accessibility to all; equity relates to equal access according to need, regardless of ethnicity, gender, age, social status or the ability to pay (ibid, p2).

This policy document continues by noting that different EU Member States have different approaches to making the values of solidarity and equity a practical reality. Differences in approaching the value of solidarity can be noted, for example, with regard to whether individuals should pay a personal contribution towards the cost of elements of their healthcare, or whether there is a general contribution, and whether this is paid for from supplementary insurance (ibid). EU Member States also implement different provisions to ensure equity; some express it in terms of rights of patients, while others in terms of the obligations of healthcare providers towards patients (ibid).

The above overarching values are supported by a set of operating principles which are also shared across EU health systems. These principles include, amongst others:

- *Quality*, in as much as 'all EU health systems strive to provide good quality care. This is achieved in particular through the obligation to continuous training of healthcare staff based on clearly defined national standards and ensuring that staff has access to advice about best practice in quality, stimulating innovation and spreading good practice, developing systems to ensure good clinical governance, and through

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<sup>4</sup> [http://eur-lex.europa.eu/LexUriServ/site/en/com/2005/com2005\\_0115en01.pdf](http://eur-lex.europa.eu/LexUriServ/site/en/com/2005/com2005_0115en01.pdf)

<sup>5</sup> [http://europa.eu/legislation\\_summaries/consumers/consumer\\_safety/c11503c\\_en.htm](http://europa.eu/legislation_summaries/consumers/consumer_safety/c11503c_en.htm)

<sup>6</sup> [http://ec.europa.eu/dgs/health\\_consumer/consumerveice/cv\\_62010\\_en.pdf](http://ec.europa.eu/dgs/health_consumer/consumerveice/cv_62010_en.pdf)

<sup>7</sup> [http://ec.europa.eu/health/strategy/docs/ev\\_20090428\\_rd01\\_en.pdf](http://ec.europa.eu/health/strategy/docs/ev_20090428_rd01_en.pdf)

<sup>8</sup> <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2006:146:0001:0003:EN:PDF>

monitoring quality in the health system. An important part of this agenda also relates to the principle of safety' (ibid, p2).

- *Safety*, whereby 'patients can expect each EU health system to secure a systematic approach to ensuring patient safety, including the monitoring of risk factors and adequate, training for health professionals, and protection against misleading advertising of health products and treatments' (ibid, p3).
- *Care that is based on evidence and ethics*, thus ensuring that care systems are evidence-based both for providing high quality care and to safeguard long-term sustainability (ibid, p3).

Citizens across the EU echo the above EU health policy concerns with quality and safety of healthcare. Nearly half the respondents to a Eurobarometer survey entitled '*Patient Safety and Quality of Healthcare*'<sup>9</sup> which examines EU patients' concerns and experiences of safety and quality of healthcare feel that they could be harmed by healthcare (both hospital and non-hospital care) in their country (p8). Citizens' perceptions of the quality of healthcare highlights that 'well-trained staff' is the most important criterion for the majority of EU citizens (52% of respondents). Citizens' descriptions of quality of care also include 'treatment that works', which 39% of respondents consider to be an important characteristic. Thereafter, 'no waiting lists', 'modern medical equipment', and 'respect of a patient's dignity' receive roughly equal responses (29%, 27%, 27%, respectively). Around a fifth of respondents state that healthcare that 'keeps you safe from harm' (22%), 'free choice of doctor' (22%), and 'proximity of hospital and doctor' (21%) are important for quality healthcare. A 'free choice of hospital' (14%) and 'a welcoming and friendly environment' (7%) were considered least important (pp53-56).

The authors of the above report also note differences concerning the importance of characteristics of quality healthcare between different EU countries as well as between different socio-economic groups, and according to gender, age and education. On a national level, there are some countries where citizens are consistently negative about the quality of available healthcare (Greece, Bulgaria, Hungary, Latvia, Lithuania, Poland) and others where citizens are consistently positive (Austria, Finland, France, Germany, Sweden).

EU health policy also considers CAM specifically. The Second Programme of Community Action in the field of health (2008-2013)<sup>10</sup> notes: 'The Programme should recognise the importance of a holistic approach to public health and take into account, where appropriate and where there is scientific or clinical evidence about its efficacy, complementary and alternative medicine in its actions (section 24, p 3)'.

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<sup>9</sup> [http://ec.europa.eu/public\\_opinion/archives/ebs/ebs\\_327\\_en.pdf](http://ec.europa.eu/public_opinion/archives/ebs/ebs_327_en.pdf) ;

<sup>10</sup> <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2007:301:0003:0013:EN:PDF>

To do so, constitutes a significant EU policy challenge as well as an opportunity, as noted in a report in 2009 by the Directorate General for Internal and External Policies to the EU president<sup>11</sup>:

A far reached inquiry into the potential of the so called alternative therapies could be a matter of relevance for Europeans in the coming decade. Moreover, as the scientific research agenda is strongly conditioned by the interests of industry, the EU could play a leading role in financing with public moneys trials to assess alternative therapies. This would set a world premier (p46).

One example of how EU policy addresses the interests of industry as well as issues of quality, safety and efficacy in relation to alternative therapies is Directive 2004/24/EC regarding traditional herbal medicinal products.<sup>12</sup> The directive establishes a regulatory process for traditional herbal medicines that aims to harmonise procedures and provisions across the EU, recognising the importance of competition between manufacturers of herbal products in different EU member states (p1). The directive seeks to ensure quality standards, safety and efficacy of herbal products through the acknowledgment of the long tradition of the use of many medicinal plants and where information on an herb's traditional use proves it not to be harmful in specified conditions of use (p1). To increase available information and scientific evidence, the directive also supports the establishment of herbal monographs as they relate to the EU Community (p2). Some however suggest that the current European legal situation, including Directive 2004/24/EC, does not sufficiently consider the special circumstances of Asian traditional medical therapies and associated medicinal products.<sup>13</sup>

The potential of alternative therapies, as noted above, and their relevance to citizens in Europe is also recognised in the EU Framework Programme 7 for Research,<sup>14</sup> under which CAMbrella is funded. With reference to 'optimising the delivery of healthcare to European citizens', FP7 highlights the importance of creating 'the knowledge bases for clinical decisionmaking and to address the translation of outcomes of clinical research into clinical practice' (p12). This includes addressing patient safety and the better use of medicines, including scientifically tested complementary and alternative medicines (ibid). Notable here, as with biomedical healthcare provision, is a focus on quality of healthcare, safety and evidence, together with the recognition of the need for more research.

In summary, this brief sketch of the EU health policy context highlights policy makers' focus on:

- Citizens as key partners in health policy development and implementation

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<sup>11</sup> [http://www.europarl.europa.eu/president/ressource/static/files/special/EU\\_Policy\\_Challenges\\_2009-19\\_-\\_Full\\_Text.pdf](http://www.europarl.europa.eu/president/ressource/static/files/special/EU_Policy_Challenges_2009-19_-_Full_Text.pdf)

<sup>12</sup> <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2004:136:0085:0090:EN:PDF>

<sup>13</sup> <http://www.eitam.eu/44.html>

<sup>14</sup> <http://cordis.europa.eu/documents/documentlibrary/90798681EN6.pdf>

- The provision of information to citizens as a means of improving their health
- Values and principles underpinning healthcare systems that aim to ensure universality, solidarity, equity, and access to good quality care of both biomedicine and CAM

These foci, together with the importance of a holistic approach to health, are also recognised as critical and valuable in CAM, and are thus supported through relevant EU research policies.

Overlapping concerns for policy makers and citizens focus on the provision of quality of healthcare and its safety, notably the training of healthcare staff. Furthermore, citizens, like EU health policies concerning healthcare systems, strongly opt for ‘treatment that works’ as a characteristic of quality healthcare. The ways of understanding and interpreting ‘treatment that works’ may differ for healthcare systems and citizens (and for different groups of citizens), and such differences may also be reflected in issues concerning citizens’ attitudes and needs regarding CAM.

## 2 Methods

Two complementary methods were used to achieve the aim, objectives, and tasks of WP3: first, a workshop was held with stakeholders concerned with and knowledgeable about citizens' needs and attitudes to CAM (see Task 1); and second, WP3 initiated a review of literature of citizens' attitudes and needs concerning CAM in Europe (see Tasks 2 and 3). Details of these methods are set out in this section.

In addition to the above, and to facilitate the collaboration between all WP3 partners, WP3 held a number of meetings and workshops: a kick-off meeting in Munich, January 2010; a second meeting to discuss interim results for Tasks 2 and 3 in Berlin, December 2010; a third meeting to finish Tasks 2 and 3 in Bologna, March 2011; and a final workshop to discuss and finalise the report in Odense, October 2011.

### 2.1 Stakeholder workshop

A two-day workshop was organised where members of WP3 met with stakeholders from across the EU to explore citizens' attitudes and needs concerning CAM. The workshop took place in Vienna (Austria), June 24-25, 2010, and was hosted by GAMED (Internationale Akademie für Ganzheitsmedizin, Vienna).

A purposeful sample of stakeholders was invited, bearing in mind a wide geographical range and the diversity of knowledge and interest in CAM. To reflect the diversity of EU countries and regions, WP3 invited experts from Denmark, Croatia, Latvia and Tuscany (Italy), complemented by the WP3 partners who are based in Denmark, Germany, Austria and France. The invited experts also reflected the diverse institutions and organisations with knowledge, concerns and interests in CAM.

The following organisations and institutions participated in the workshop:

- Croatian Federation of Natural, Energy and Spiritual Medicine, Croatia
- Danish Consumer Council, Denmark
- Riga Stradin University, Latvia
- Tuscan General Direction of Health, Tuscany, Italy

The workshop had three key aims:

- To identify how to explore citizens' attitudes and needs to CAM
- To facilitate the sharing of relevant sources of information about CAM that exists across the EU

- To help identify how citizens' attitudes and needs to CAM can be measured and compared across the many EU countries.

A broad range of themes relevant to citizens' attitudes and needs concerning CAM were discussed during the two-day workshop. Each participant contributed a presentation in their field of expertise which then provided the basis for further discussion and work in small groups.

Themes discussed included:

- CAM in the context of EU health policies
- CAM integration into public healthcare systems
- Consumer rights and safety issues with regard to CAM
- Citizens' information needs about CAM
- Indications of citizens' attitudes and needs concerning CAM based on academic literature

The presentations and discussions throughout the workshop and during the final plenary highlighted the interrelationship between citizens' attitudes to CAM and their needs, and the participants identified three important issues relating to EU citizens' needs concerning CAM:

- Independent and easily accessible information about CAM, based on the strength of available evidence to support informed decision-making
- Quality of care, comprising services, practitioners and products
- Equal access to services, including consideration of geographical distance to services, waiting times and costs/reimbursement

These three key issues were subsequently transformed into literature search terms which, together with other search terms, broadly reflect a range of indicators for needs (see Section 2.2.1). In this way, the stakeholder workshop both provided the basis for developing relevant indicators for citizens' needs concerning CAM, as well as contributed to inform the overview of literature which explores citizens' attitudes and needs concerning CAM.

Following the workshop in Vienna, a questionnaire was sent to national CAMbrella representatives and the workshop participants in order to identify additional stakeholders. Key persons and institutions have been identified in all but three countries (Albania, Luxemburg and Macedonia) in the EU and associated states. This information was merged into a central CAMbrella document that combines complementary information collated by other WPs.

## 2.2 Review of literature about citizens' attitudes and needs concerning CAM in Europe

For the review of literature concerning citizens' attitudes and needs concerning CAM an early decision was made by the WP3 partners to focus on academic peer-reviewed literature only. This focus, it was concluded, would enable the identification of the current state of research about citizens' attitudes and needs based on the most reliable available information, and would therefore best meet the aim and objectives of WP3.

### 2.2.1 Identifying the literature: Search strategies and literature searches

WP3 developed a comprehensive literature search strategy which sets out the decisions made concerning the implementation of the searches, taking the search strategies of other WPs into consideration. The databases used and the search terms developed relied upon English as an international language; alongside care was taken to use databases and develop search terms that enabled the targeting of a very broad spread of different CAM therapies and therapeutic approaches in different EU countries. Details of the search strategy, including the choice of databases, inclusion and exclusion criteria, limits of searches, and search terms are provided in Appendix 1 and 2.

Two separate but related main searches were carried out, referred to as Search 1 and Search 2. In addition to general search terms (see Appendix 2.1 and 2.2) Search 1 used three key terms – citizen, need, and attitude – and a number of synonyms (see Appendix 2.3) in combination with terms for CAM and Europe (plus Turkey and Israel) or individual European countries, including Turkey and Israel (see Appendix 2.1). This search identified a total of 2.796 abstracts of which 323 met in/exclusion criteria (see Appendix 3, Table 2).

Search 1 identified few abstracts relating to citizens' needs regarding CAM in Europe, when compared to the number of abstracts relating to citizens' attitudes to CAM in Europe. To identify abstracts relating to citizens' needs a second search, Search 2, was carried out. Sources for search terms for Search 2 comprised: recurring key terms in Search 1; key points identified by stakeholders (see Section 2.1); and terms derived from the CAMbrella proposal (see Appendix 2.4). Search 2 identified 3.698 abstracts of which 194 met in/exclusion criteria (see Appendix 3, Table 3).

After removing duplicates from Searches 1 and 2, 338 abstracts met in/exclusion criteria and full articles were retrieved. These can be broken down into:

- 216 articles reporting on quantitative studies
- 57 articles reporting on qualitative studies
- 22 literature reviews
- 43 abstracts only

All articles were then read and a number of them further excluded as not meeting in/exclusion criteria. Where only abstracts were available, these were also rejected at this point, as were non-systematic literature reviews (see Flow diagram 1 below). This resulted in 189 articles which can be divided as follows:

- 150 articles reporting on quantitative studies
- 36 articles reporting on qualitative studies
- 3 systematic reviews of literature

These 189 articles constitute the basis for the findings presented and discussed in this report.

## 2.2.2 Working with the identified literature

Before the content of the identified articles was analysed, some preliminary work was carried out. This focused on: assessing the quality of reporting of the studies; and evaluating the relevance of the identified articles for the work of WP3. These aspects are described in the next sections, followed by a summary of analytic strategies.

### *Assessing the quality of reporting of quantitative and qualitative studies*

To evaluate the reliability of information provided in the articles, the quality of the reporting of the studies was assessed. This assessment of the quality of reporting does not reflect the quality of the studies that are reported in the articles, nor does it comment on this.

The quality of the reporting in the articles on quantitative studies was assessed drawing on guidelines by Elm E, Altman DG, et al. (2007), The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: Guidelines for Reporting Observational Studies, *Annals of Internal Medicine* 147, 8: 573-577 (see Appendix 4).

The quality of the reporting in the articles of qualitative studies was assessed drawing on guidelines by Malterud K (2001), Qualitative Research: Standards, Challenges and Guidelines, *Lancet* 358: 483-488 (see Appendix 5).

Based on the quality assessment, articles were then grouped into three 'reporting quality' categories: high, medium and low (see Flow diagram 1 below and Appendix 4.2 and 5.2). Of 186 articles (excluding systematic reviews of literature), 43 were considered high quality reporting, 96 medium and 47 low quality reporting. Flow diagram 1 below summarises this process and Appendix 4 and 5 provide more details on the assessment of the reporting quality.

### *Evaluating the relevance of the identified articles to the work of WP3*

Already during the earlier stage of searching the literature, it was noted that there seemed to be few studies that address citizens' attitudes and needs regarding CAM directly, and

that much of the information available on this subject was incidental to the research focus of many studies. To gain greater clarity on this, a scoring system was developed that would help to identify studies that directly addressed research questions concerning citizens' attitudes and needs regarding CAM and others that did so indirectly, as part of other research foci. The scoring system used is as follows:

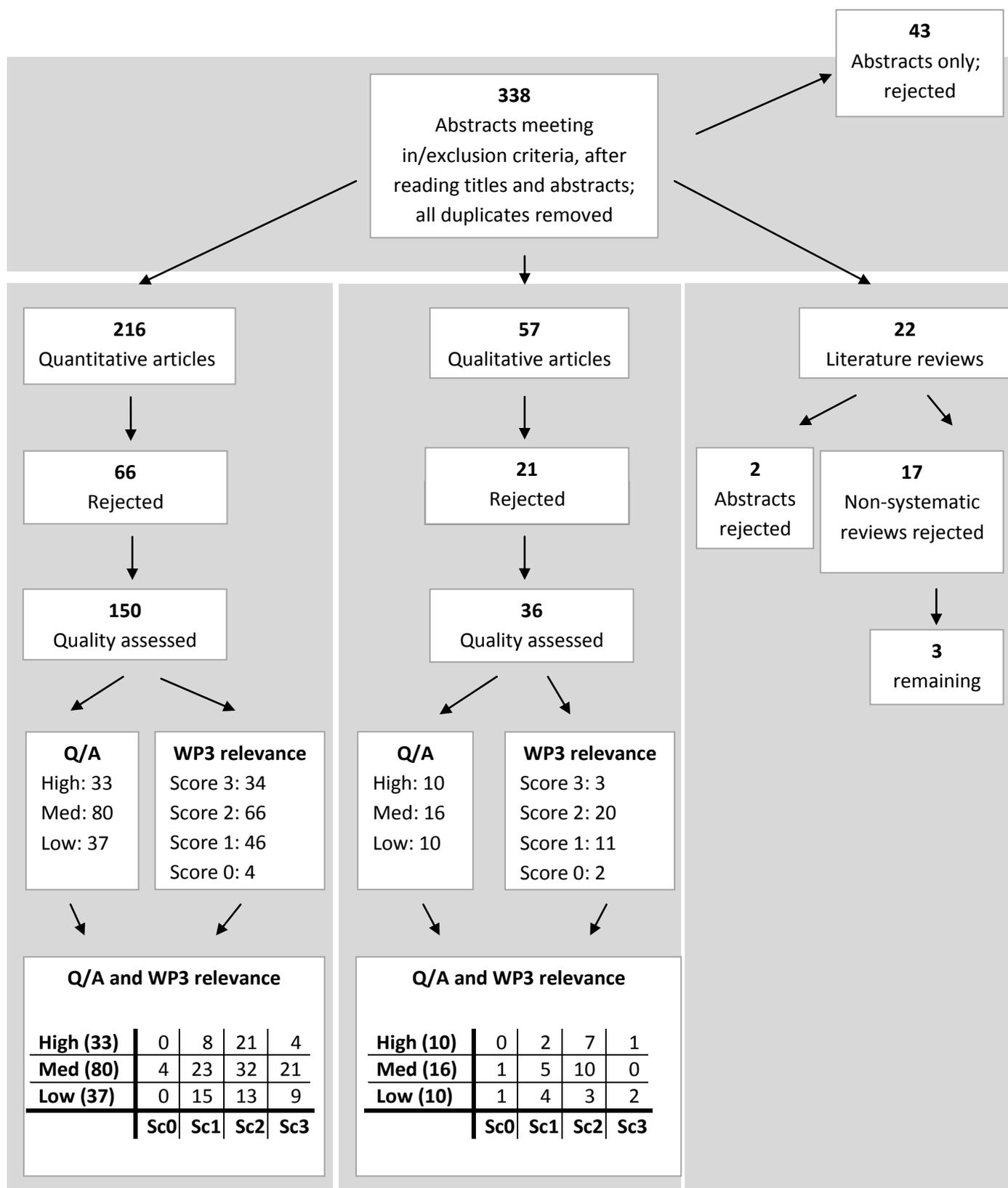
- Score 3 – studies that directly addressed a research question of relevance to WP3 (e.g. a research question exploring citizens' attitudes to CAM)
- Score 2 – studies that indirectly addressed several issues concerning citizens' attitudes or needs regarding CAM (e.g. a survey may aim to establish levels of CAM use in a population, and may include questions relevant to WP3, for example: a question about sources of information about CAM used, a question about disclosure of CAM use to biomedical professionals, and a question about reasons for CAM use)
- Score 1 - studies that indirectly addressed only one issue concerning citizens' attitudes or needs regarding CAM (e.g. a survey may aim to establish levels of CAM use in a population, and may include a question relevant to WP3, for example: a question about sources of information about CAM used )
- Score 0 – studies not addressing any issues identified as relevant to WP3

It should be noted that a low score for relevance does not imply that the information presented is lacking in importance, but that there is less information available, compared to a Score 2.

The scoring for relevance highlights that of the 186 quantitative and qualitative articles included in this review, only 37 articles directly address citizens' attitudes or needs, or both. The majority of articles addresses issues pertaining to citizens' attitudes and needs only in indirect ways, that is, as part of studies with other main foci. For further details, see Flow diagram 1 and Chart 1, below and Appendix 4 and 5.

#### *Quality of reporting and WP3 relevance*

The results of the assessment of the quality of reporting and of WP3 relevance can be brought into dialogue by combining the figures presented in the breakdown of quantitative and qualitative articles and their assessment for quality of reporting and relevance to WP3 (see tabular charts in Flow diagram 1). This then presents the total number of articles with regard to their quality of reporting and relevance to WP3 (see Chart 1) identified in the literature searches.



Flow diagram 1: Breakdown of identified abstracts and articles

What emerges is that the literature searches have identified only 5 articles considered in this review of high quality reporting which address a research question(s) directly relevant to the work of WP3, and 32 articles of medium and low quality reporting which do so. All

other articles address relevant issues indirectly. This highlights that citizens' attitudes and needs concerning CAM in Europe constitute a significantly under-studied area of research.

<b>High Q/A (43)</b>	0	10	28	5
<b>Medium Q/A (96)</b>	5	28	42	21
<b>Low Q/A (47)</b>	1	19	16	11
<b>Total Q/A (186)</b>	6	57	86	37
	<b>Score 0</b>	<b>Score 1</b>	<b>Score 2</b>	<b>Score 3</b>

Chart 1: Assessment for quality of reporting and evaluation of WP3 relevance (excluding systematic reviews of literature)

### *Analysis of the content of the identified articles*

All the identified articles were gathered into an Endnote library and grouped according to 'quantitative' or 'qualitative' articles, and systematic literature reviews. Using the Endnote 'label' function, several details were recorded for each article: the assessment score of the reporting quality; the relevance score; country in which study was carried out; broad themes arising from early reading of the articles. This allowed for searching and grouping different articles into a number of sub-groups for further thematic analysis.

## **2.3 Methodological considerations: Limitations and challenges**

This section explores some of the methodological limitations and challenges encountered during this review, reflecting in particular on the databases and search terms used, English as the language of research, and the diversity of studies identified.

One of the challenges for current research in the field of CAM is the lack of a shared understanding of the term CAM. In the endeavour to identify a broad range of relevant literature across the EU, we used a number of search terms associated with the term 'CAM' and variations thereof (e.g. those contained in the Pubmed MeSH term 'complementary therapies'; see Appendix 2.1). However, there are many locally specific terms in circulation that may differ from those used by the databases utilised, and in some EU countries some health practices may be considered locally to be traditional or folk medicine (and designated as such) rather than a form of CAM. As a result of the choice of search terms, articles that may have been relevant to WP3 may not have been identified.

The focus on academic peer-reviewed articles as the basis for this report also has implications. International databases rely on English as the language of research and thus focus on English language publications, at the expense of other EU languages, even though

all identified abstracts and articles written in German, Danish, Norwegian, Spanish and Italian, in addition to English, were integrated into this review. Abstracts in other EU languages were not followed up. In addition, the focus on databases excluded the addition of other publications, such academic anthologies, governmental reports and surveys, or publications by CAM organisations.

Lastly, both the quantitative and qualitative studies identified through the literature searches draw on a great number of different methodologies and approaches to data collection, cover a wide range of research questions, and originate from diverse disciplinary backgrounds. This has made the assessment of the quality of reporting challenging.

In summary, the research methods adopted by WP3 blend the participatory method of a stakeholder workshop that reflects a wide range of organisations and institutions across the EU with knowledge and expertise in citizens' attitudes and needs in Europe with a comprehensive review of peer-reviewed literature. The stakeholders pointed towards three key issues concerning citizens' attitudes and needs regarding CAM in Europe – information about CAM, quality of care in CAM, and access to CAM. These key issues resonate with the common values and principles that underpin EU health systems (see above). The findings of the literature review highlights that these key issues also emerge in the analysis of the articles identified, and are turned to next.

### 3 Overview of citizens' attitudes and needs concerning CAM in Europe

The themes and issues emerging from the analysis of the 189 articles included in this review echo the key issues concerning citizens' attitudes and needs identified by the WP3 stakeholder workshop in Vienna, as well as noted in EU health policies. The findings presented in this section therefore cover three overarching topics:

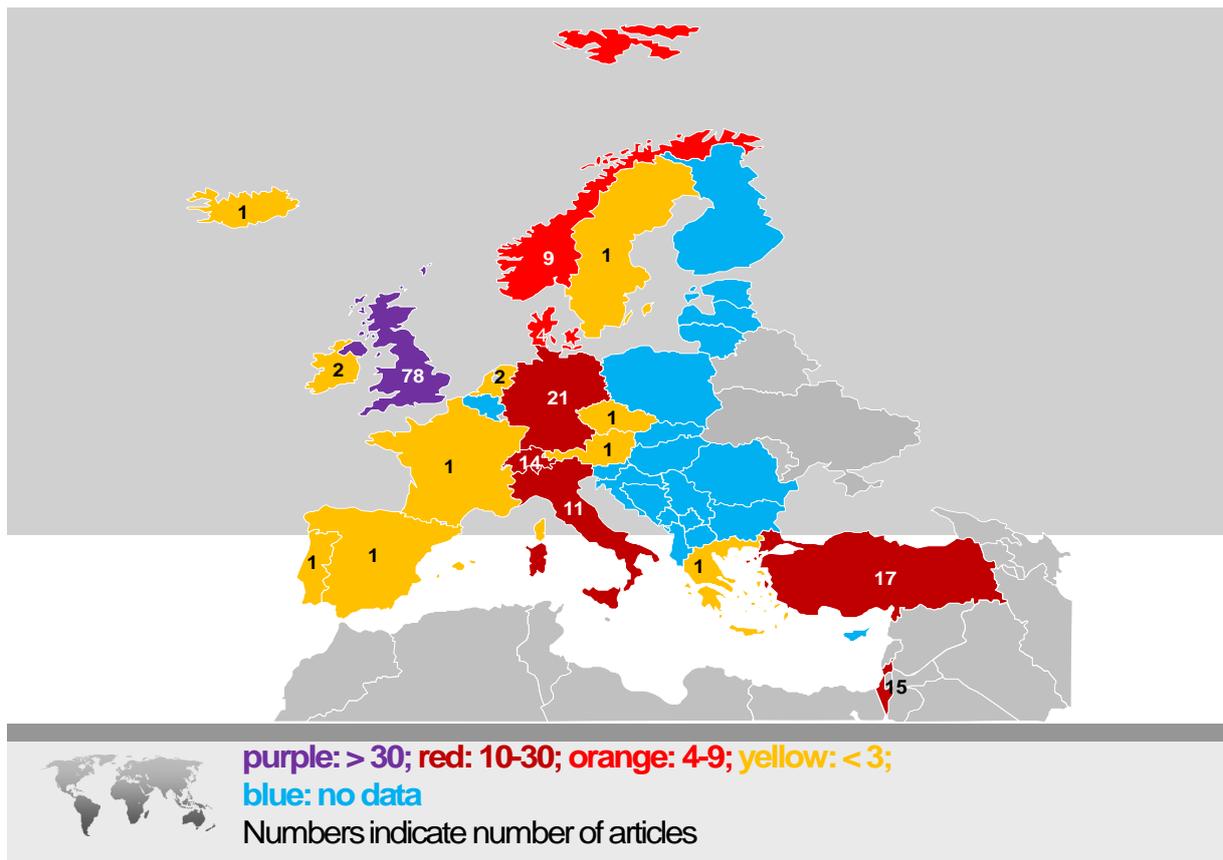
- Information about CAM
- Access to CAM
- Quality of care in CAM

These three topics run through this findings section like a 'red thread'.

Before exploring each of the above topics in turn, an overview of the geographical distribution of the identified articles helps to contextualise the availability of knowledge across the EU. This shows the following broad pattern:

- Prominence of the UK (78 articles),
- A diversity of countries with a medium-range of articles, such as Germany (21 articles), Turkey (17 articles), Israel (15 articles), Switzerland (14 articles), and Italy (11 articles),
- Several countries with a small number of articles,
- Countries where no peer-reviewed articles were identified.

Map 1 illustrates the distribution of articles across the EU (excluding EU wide studies and the three systematic reviews of literature), and Table 1 provides additional details.



Map 1: Distribution of identified articles across the EU

> 30 articles	10-30 articles	4-9 articles	< 3 articles	No articles	
UK 78	Germany 21 Turkey 17 Israel 15 Switzerland 14 Italy 11	Norway 9 Denmark 4	Ireland 2 Netherlands 2 Austria 1 Czech Republic 1 France 1 Greece 1 Iceland 1 Portugal 1 Spain 1 Sweden 1	Albania Belgium Bosnia and Herzegovina Bulgaria Croatia Cyprus Estonia Finland Hungary Iceland Latvia Lithuania Luxemburg Macedonia Malta Poland Romania Serbia Slovakia Slovenia	Europe as a whole: 5

Table 1: Number of articles per EU country

The identified geographical distribution of articles thus highlights the following ‘extremes’:

- A dominance of UK based articles
- Little or no knowledge about many EU countries

These differences are important to bear in mind when considering the following sections. Other considerations when reading this report are summarised in Box 1 below.

**Box 1: Notes to the reader**

- *The presentation of quantitative and qualitative studies:* Many of the quantitative studies included in this overview have a high number of participants when compared to qualitative studies. While qualitative studies are valuable and valid in their own right, in this report findings resulting from such studies are largely used illustratively, with relevant detail summarised in boxes.
- *The use of the assessed quality of reporting of the articles identified for this overview:* Articles assessed as high quality reporting inform the main points presented in the finding sections; other articles are used supplementary to these. Details about the quality of reporting of each article are provided in the reference list at the end of this report.
- *Use of systematic reviews of literature:* These are used to cross-check for patterns and trends noted in the literature identified for this review.
- *Presentation of statistical details:* In articles where percentages of results were presented with great statistical details, these have been rounded up/down to the nearest whole number.
- As noted in Section 2.2.2, *the majority of articles identified for this review addresses issues relevant to WP3 in indirect ways:* Accordingly, while every effort has been made to refer to as many articles as possible in the context of each overarching topic, not every single article which may have referred to one of the three key topics is discussed and listed in the maps accompanying each section.

### 3.1 Citizens’ attitudes and needs concerning ‘information about CAM’

The literature searches have identified a considerable number of studies concerned with citizens’ attitudes and needs regarding information about CAM. When the flow of information is understood as a two-way process, citizens’ attitudes to seeking information about CAM, as well as their attitudes to providing information about their use of CAM to biomedical professionals can be recognised.

With regard to citizens’ attitudes to seeking information about CAM, the following four main themes can be identified from the literature:

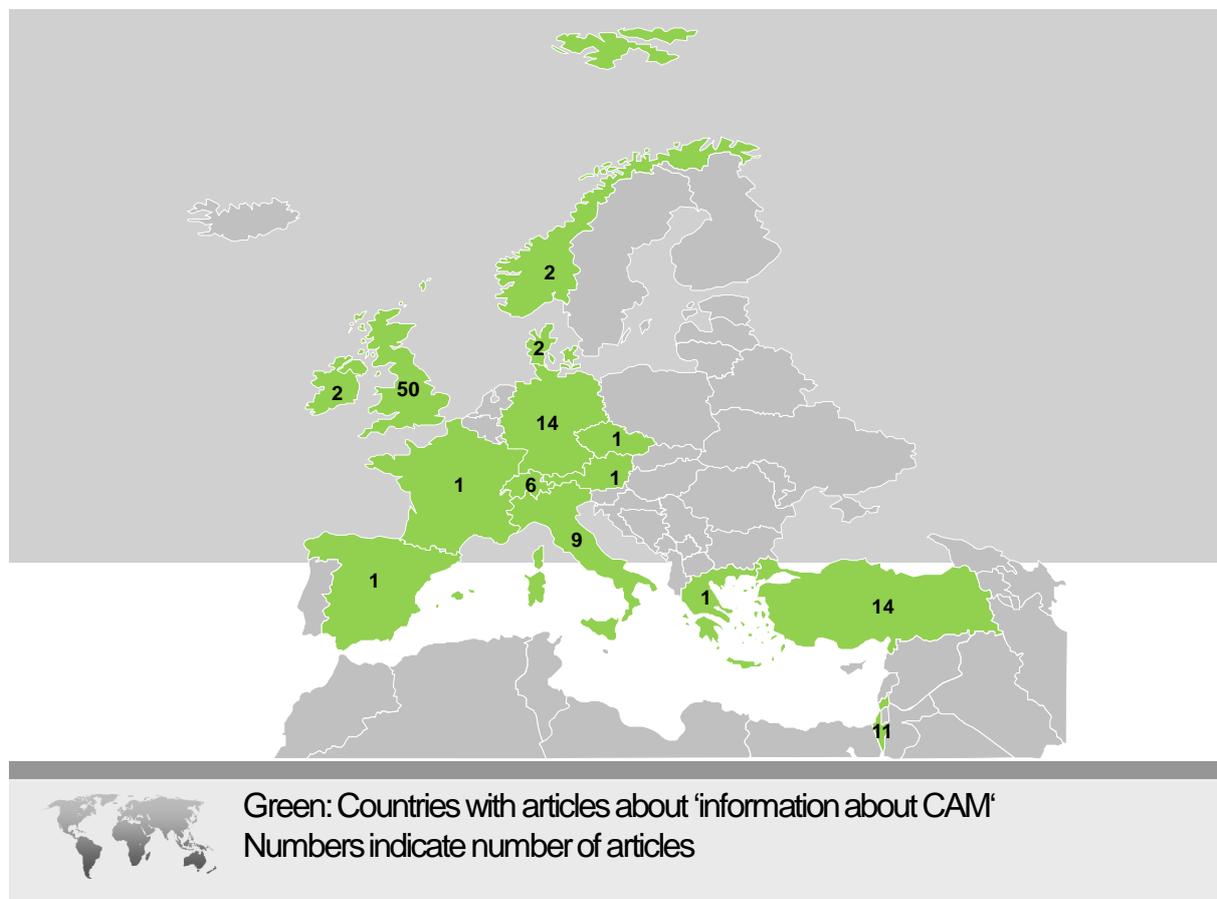
- The importance of citizens’ social networks as sources of information about CAM and its recommendation, together with a relative lesser importance of gathering information from biomedical professionals

- The centrality of biomedical professionals as source of information and recommendation, together with a relative lesser importance of social networks as source of information
- The significance of individuals' personal experience with CAM in the sharing of information about CAM
- Citizens' use of various media and other sources of information to make themselves knowledgeable about CAM

In addition, citizens' attitudes to providing information about their interest in or use of CAM to biomedical professionals are prominent in this body of literature, and these are explored through citizens' disclosure or non-disclosure of CAM use to biomedical professionals and their explanations for their actions.

Together, these issues point towards a multi-dimensional decision-making environment concerning the use of CAM in which the availability – or lack - of reliable and trustworthy information about CAM plays a central role.

Approximately 115 articles were identified which address issues relating to the topic of information about CAM (see Map 2). These articles report on studies in individual countries, EU wide studies, and systematic reviews of literature.



Map 2: Countries with articles which address issues concerning 'information about CAM'

### 3.1.1 Citizens' attitudes to diverse sources of information

Citizens can be noted to draw on three main sources of information to make themselves knowledgeable about CAM:

- Citizens' personal social networks
- Biomedical professionals
- Print and broadcast media

The ways in which these three main sources of information about CAM are prioritised and combined by citizens in different EU countries are examined in this section.

#### *Social networks as source of information about CAM*

For many citizens information sources about CAM are closely tied up with their social networks of family, friends, colleagues and other close associates. It is individuals within these networks who often advise on, suggest or recommend the use of CAM, either by a CAM provider or the purchase of a CAM product. In countries where social networks constitute a main source of information, biomedical healthcare professionals as information sources appear to be comparatively less important. This pattern is especially noticeable in, but not exclusive to, the UK, Turkey, Israel, Norway and Ireland (see Table 2, below).

#### *Studies from the UK*

In the UK, the most commonly reported source of information is a friend, relative or colleague who is part of individuals' various social networks. Concerning the extent to which individuals draw on their social networks as source of information for CAM, findings from UK surveys are very diverse. The majority of surveys identify figures of approximately 50% to 60%, across a range of health complaints, different groups of citizens, and different CAM therapies (Artus et al., 2007; Domoney et al., 2003; Emslie et al., 1996; Gerasimidis et al., 2008; Johnston et al., 2003; Robinson et al., 2008; Shakeel et al., 2008b; Simpson & Roman, 2001; Strutt et al., 2008; Thomas & Coleman, 2004; Thompson et al., 2007). Some surveys group together sources of information and recommendations through social networks with self-initiated CAM, leading to figures of around 75% (Cincotta et al., 2006; Crawford et al., 2006). Figures from other surveys range from as low as 28% for men with prostate cancer (Wilkinson) and 33% for acupuncture (Macpherson et al., 2004) to as high as 87% in children with skin complaints (Johnston et al., 2003), and 97% for patients with musculoskeletal complaints (Chandola et al., 1999).

Qualitative studies also note the importance of family and other social networks in providing information about CAM and introducing people to it (Badger & Nolan, 2007; Badone, 2008; Evans et al., 2007a; Evans et al., 2007b; Frank & Stollberg, 2004a; 2004b; Furnham, 2002; Green et al., 2006; Rhodes et al., 2008; Shaw et al., 2006a). In addition, these qualitative studies point towards specific groups in these networks as being particularly important in directing individuals towards CAM. These groups include: female

family members of male cancer patients (Evans et al., 2007a; Evans et al., 2007b); older family members in the case of people of South Asian origin in the UK (Rhodes et al., 2008); Chinese migrant women's networks that may span the UK and women's countries of origin (Green et al., 2006).

By comparison with the centrality of social networks in providing information about CAM in the UK, most of the above studies note that few citizens seek information about CAM from biomedical healthcare professionals, and only few biomedical professionals discuss or recommend the use of CAM (see also, Maha & Shaw, 2007; Moody et al., 1998). Figures vary from 6% of doctors (Crawford et al., 2006) to 24% of doctors informing about and/or suggesting the use of CAM (Domoney et al., 2003) and 28% of a range of biomedical professionals informing and recommending CAM use (Emslie et al., 1996).

Within this general pattern of information provision by doctors and/or broader groups of biomedical professionals in the UK who inform about, recommend and/or refer to CAM, two trends can be noted. First, women with hormonal complaints and children appear to be recommended CAM or referred more frequently by their general practitioners than some other groups of patients (for example, Domoney et al., 2003; Fearon, 2003; Gerasimidis et al., 2008; Robinson et al., 2008; Vashisht et al., 2001). Second, a higher percentage of citizens are provided with information about CAM and/or recommended and referred for CAM treatment when surveys combine different groups of biomedical professionals (for example, Emslie et al., 1996; Holst et al., 2009b; Shakeel et al., 2008b). This last point might suggest that different groups of biomedical professionals in the UK, such as general practitioners, hospital doctors, nurses, midwives or pharmacists, may have different attitudes to CAM. However, not all studies support this observation (see Johnston et al., 2003).

Several UK qualitative studies further explore the possible differences between different groups of biomedical professionals in providing information (Evans et al., 2007b; Tovey & Broom, 2007). These studies also examine the implications this might have for citizens, and citizens' expectations regarding accessing information about CAM (see Box 2).

**Box 2: Accessing information about CAM from different biomedical professionals: perspectives from qualitative research**

Tovey et al. (2007) examine cancer patients' experiences in discussing CAM with oncologists and specialist cancer nurses in the UK. Patients reported three main types of approach by oncologists: explicit or implicit negativity; supportive ambivalence; and, pragmatic acceptance. Patients' accounts indicate that the type of approach adopted by their oncologists influences, though does not determine, their actions in relation to CAM. The authors suggest that specialist cancer nurses may potentially be powerful mediators between patients and oncologists with possibly negative attitudes to CAM. In particular, nurses with a commitment to CAM may be the patients' first point of contact for CAM information, leading to patients trying out CAM for the first time. The important role of specialist nurses in advising about CAM is also noted by Shaw et al. (2006b).

The male cancer patients in Evans et al.'s (2007b) UK study identify a general lack of CAM information from biomedical professionals in the NHS. Accordingly, men in this study became either 'pro-active seekers' or 'passive recipients' of such information. Some men described how their 'passive' role sometimes arose as a result of the lack of open discussion about CAM within the NHS and the difficulty they experienced in raising the subject. This experience led some men to speculate whether oncologists' reluctance to engage with the topic was driven by individual disinterest or skepticism, or by hospital policy. Others, however, responded to the lack of CAM information available from NHS health professionals by taking on a pro-active information-seeking role. At a minimum, many of these men felt that NHS professionals should adopt a 'signposting' role by providing CAM information about resources and practitioners.

While these findings from both quantitative and qualitative studies indicate a trend that UK biomedical professionals provide less information on CAM than citizen access through their social networks, this is not to suggest that citizens would not like to receive information from biomedical professionals about CAM (Evans et al., 2007a; Fearon, 2003; Richardson, 2004; Shaw et al., 2006b; Williams & Mitchell, 2007), particularly practice or specialist nurses (Shaw et al., 2006b). Indeed, Holst et al. (2009b) mention that those citizens who do not use CAM and have not used it in the past prefer biomedical professionals as sources of information.

*Studies from various EU countries*

A similar pattern concerning attitudes to information about CAM can be observed in other EU countries, though there are significantly less studies available than for the UK. For Turkey, several studies confirm the importance of social networks for gaining information about CAM therapies (Algier et al., 2005; Arguder et al., 2009; Aydin et al., 2008; Ceylan et al., 2009; Ceylan et al., 2002; Er et al., 2008; Kara, 2009; Karadeniz et al., 2007; Kav, 2009; Ozturk & Karayagiz, 2008; Yilmaz et al., 2007). Here, figures range from about 30% to 84% to people accessing information through their social networks, across a range of user groups and health complaints. At the same time, around 10% of Turkish citizens gather information about CAM from biomedical professionals (Algier et al., 2005; Aydin et al., 2008; Kav, 2009).

Likewise for Israel, several studies highlight diverse social networks as main information source about CAM, with a relative lack of importance of biomedical professionals. Between

41% and 90% of citizens draw on their social networks as information source (Hana et al., 2005; Pud et al., 2005; Shmueli & Shuval, 2004), while doctors are used as such by around 10% to 16% (Hana et al., 2005; Pud et al., 2005) and nurses by about 5% (Pud et al., 2005) of citizens. According to Bernstein et al. (1997) though, most medical doctors refer patients for CAM treatment, frequently at the request of patients. These findings about Israeli citizens' current practice concerning information about CAM contrast sharply with their expectations: both women and men, and Arabs and Jews expect their family physician to have knowledge about CAM so that they can provide both information and referral when appropriate, if not offer treatment themselves (Ben-Arye et al., 2008; Ben-Arye et al., 2009c; Ben-Arye et al., 2009a). Israeli nurses on the other hand feel that both nurses and GPs have a role in providing information and recommendations about CAM (DeKeyser et al., 2001).

The importance of family and friends as main source of information about CAM is also noted for Ireland, Norway and Switzerland. An Irish study reports that 51% of pediatric patients use friends and family as their main information source (Low et al., 2008) and 33% of Norwegian cancer patients do so, where, in addition, the limited input of doctors is noted (Risberg et al., 1997). Swiss cancer patients also receive information about anthroposophical medicine predominantly from friends and family (43%) compared to biomedical professionals (20%) (von Rohr et al., 2000).

Studies which examine CAM across Europe (Anelli et al., 2002; Molassiotis et al., 2005a; Molassiotis et al., 2005b; Molassiotis et al., 2006a; Molassiotis et al., 2006b) and in a wider range of EU countries than mentioned above, confirm the importance of social networks. Anelli et al. (2002) examine homeopathy in Belgium, France, Italy, Portugal, Spain and Switzerland and note that the majority of patients (84%) received information about homeopathy and homeopaths from family and friends. Likewise, the majority of cancer patients (86%) participating in Molassiotis et al.'s (2005a) study learnt about the CAM therapy they used from friends and family. The 13 countries in which this study was carried out are: Belgium, the Czech Republic, Denmark, England, Greece, Iceland, Israel, Scotland, Serbia, Spain, Sweden, Switzerland and Turkey.

While the majority of studies examined so far, consider CAM as offered or supplied by CAM providers, sources of information that lead to the purchase of CAM products are also mentioned in some studies. Here too, the importance of social networks is noted, especially when buying herbs and/or herbal products: available figures range from 53% of participants in samples in Italy (Zaffani et al., 2006; see also Bacchini, et al, 2008), to 63% in Germany (Hartel & Volger, 2004) and 70-85% in Turkey (Aydin et al., 2008; Kara, 2009; Yilmaz et al., 2007) as relying on their social networks for information; a majority of pregnant women on a Norwegian are also said to do so (Nordeng & Havnen, 2004). A similar picture is presented concerning the purchase of over-the-counter homeopathic remedies in the UK, with 45% of buyers drawing on their social network for information and 10% being prompted by their doctor (Reid, 2002).

### ***Biomedical professionals as main source of information***

The second pattern of information seeking involves general practitioners and other biomedical professionals as main information source about CAM. Where this is the case, information provided by social networks is comparatively less prominent though still important. This pattern, albeit not clear cut, is particularly observed in Germany and Italy.

In Germany information about CAM is often provided by physicians (see e.g. Schwarz et al., 2008), when compared to other sources of information. Variations between different groups of physicians can be noted, and differences between CAM administered by a CAM provider and citizens' independent use of CAM products are also reported. In samples from particular patient groups, 60% to 84% of participants gathered information about CAM from physicians (Joos et al., 2006; Nagel et al., 2004). By contrast, 44% of participants in a population – based survey reported to have used physicians as source of information, while 43% also noted that the 'most influential' information about CAM was received from members of their social networks (Bucker et al., 2008). Specialist physicians as information source were reported by 25% of participants in Bucker et al.'s (2008) study and 29% of participants in Joos et al.'s (2006) study.

Despite the overall important role of biomedical professionals as providers of information in Germany, not all information about CAM is accessed in this way: for 63% of a sample of people the use of herbal remedies was initiated by themselves or through information from their social network (Hartel & Volger, 2004); for 50% of a sample of patients friends and family provided information about CAM and physicians 25% (Wasner et al., 2001).

In Italy, the picture about who acts as main information source about CAM – biomedical professionals or social networks - is even less clear than in Germany, and points towards differences relating to CAM therapies. In Tuscany, 58% of a sample of general practitioners are said to recommend CAM to their patients (Giannelli et al., 2007), while a nation-wide survey suggest that 38% of Italian citizens receive information and advice about CAM from their GPs (Menniti-Ippolito et al., 2002). Furthermore, differences in sources of information depending on CAM therapy are identified in some Italian studies: for 42% of Dello Buono et al.'s (2001) participants the use of acupuncture was suggested by a GP or a specialist, whereas relaxation techniques were suggested by 22% of GPs and specialists (18% and 4% respectively). Likewise, for users of homeopathy biomedical professionals were less common sources of information than citizens' social networks (Pomposelli et al., 2006).

### ***The importance of personal experience with CAM***

Underpinning the sharing of information through social networks is the importance of personal experience with CAM. Citizens' personal experience can be seen to critically influence both the initial and repeated use of CAM. The trend of attitudes to CAM being shaped by personal CAM experience can also be observed for biomedical professionals.

### *The sharing of personal experience with CAM*

Some quantitative studies, including from the UK, Ireland, Germany, and Switzerland, note that other patients with a similar or the same health complaint or shared health needs provide information about CAM to others. This exchange of information can take place individually, through self-help groups, particular clinic settings (such as ante-natal clinics), or religious groups (Bucker et al., 2008; Corner et al., 2009; Er et al., 2008; Low et al., 2008; Molassiotis et al., 2005a; Nagel et al., 2004; Pud et al., 2005; Quattropani et al., 2003; Wasner et al., 2001).

The centrality of individuals' personal experience and their individual stories in passing on information about CAM to family, friends and other close associates is most closely examined in qualitative studies. (for example, Badone, 2008; Evans et al., 2007a; 2007b; Rhodes et al., 2008) (see Box 3). In addition, several of these studies cite CAM users who were encouraged by family members in their initial CAM use, despite their own skepticism. The decision to consult a CAM provider can therefore be grounded in others' positive experience and conviction about CAM, and may in the course of CAM use become a shared attitude based on personally meaningful experiences.

#### **Box 3: Personal experiences with CAM as a way of making one's judgment about CAM**

A number of qualitative studies explore how and why individuals' draw on their own experience or the experiences of others in making their judgments about their personal use of CAM.

Evans et al.'s (2007b) participants formed their own judgments about CAM on the basis of their own story of surviving cancer and the particular benefits they perceive. Similarly, a participant in Badone's (2008) study gained confidence in using a particular CAM provider based on her sister's experience. This was further bolstered when many things about the participant's personality, past life and illness that resonated with her own judgment and understanding of her situation were revealed to her by the healer.

The reasons why individuals rely on their social networks as important information source is explored in a focus group discussion of pregnant women using herbal remedies in the UK (Holst et al., 2009a). Asking family and friends was mentioned as a way of gaining experience: 'Just like when you do parenting, you talk to people who you respect as parents and then you ask them' (ibid, p227). The respect in trusted individuals and their experience is contrasted by these women with their lack of trust in the pharmaceutical industry which produces and markets many herbal products in the UK as elsewhere. As the aim of the pharmaceutical industry is to make profit, the information provided was not considered to be sufficient or entirely trustworthy (Holst et al., 2009a).

### *Personal experience and its influence on future choices concerning CAM use*

The importance of positive personal experience can also be seen in CAM users' intentions of using a previously used CAM modality again in the future. For the UK, CAM users' intentions of repeated use range from 87% to 95% (Artus et al., 2007; Emslie et al., 1996; Xing & Long, 2006); in Norway, 84% of acupuncture users would use the therapy again (Norheim & Fonnebo, 2000). CAM users frequently also recommend a clinic or therapy: for

instance, 86% of Xing et al.'s (2006) UK participants would recommend the acupuncture clinic to a friend, and in Switzerland 95% of respondents would recommend the methods they had used themselves (Kristof et al., 1998). Similarly, Austrian (Schernhammer et al., 2009) and Swiss (Augustin et al., 1999) studies note the importance of personal experience in the development of positive perceptions of CAM.

This trend of attitudes to CAM being shaped through personal experience is also noted with reference to biomedical professionals. In a survey of decision-makers in German medical schools, Brinkhaus et al. (2005) find that decision-makers positive opinions about CAM are based on personal experience (74%), followed by scientific research (46%) or personal conviction (45%). On the other hand, negative opinions about CAM were primarily informed by scientific research (74%), personal experience (46%) and personal conviction. This trend is further supported by research amongst physicians in Germany (Munstedt & von Georgi, 2005) and Switzerland (Marian et al., 2006; Siegenthaler & Adler, 2006), and nurses in the UK (Fearon, 2003) and Switzerland.

Likewise, the attitudes to CAM of students in biomedical disciplines seem to be influenced by their experiences. The majority of Danish medical students (68%) has tried and would recommend herbal medicine supplements, acupuncture and reflexology to friends (Damgaard et al. 2008). In the UK, just under half of pharmacy students (43%) have used some CAM therapies, especially aromatherapy, Traditional Chinese medicine and herbal medicines, and would like to see these therapies to be made available on the National Health Service (Freymann et al., 2006). In the Czech Republic, a majority of pharmacy students (92%) reported the personal use of medicinal herbs (80%), massage (61%) and relaxation techniques (57%) and would recommend these therapies in particular (Pokladnikova & Lie, 2008). Turkish student nurses also would like to see the CAM therapies they use for self-care integrated into the curriculum (Oztekin et al., 2007).

### ***Other sources of information about CAM***

In addition to social networks and/or biomedical healthcare professionals, citizens across the various EU countries also draw on other information sources about CAM. These sources include particularly different forms of media and CAM providers.

#### ***The media***

A number of studies in various EU countries highlight the importance of diverse forms of print and broadcast media, though it is not always clear what precisely is included in this broad category; some studies include books as well as the internet, others exclude the internet, and/or refer to TV, radio, newspaper and magazines. The use of a variety of media is noted in studies from the following countries: UK (Domoney et al., 2003; Gerasimidis et al., 2008; Johnston et al., 2003; Reid, 2002; Shakeel et al., 2008a); Italy (Menniti-Ippolito et al., 2002; Pomposelli et al., 2006; Zaffani et al., 2006); Germany (Bucker et al., 2008; Hermes et al., 2004; Laengler et al., 2008; Nagel et al., 2004; Wasner et al., 2001); Turkey (Algier et al., 2005; Arguder et al., 2009; Kav, 2009; Uzun & Tan, 2004); Israel (Brook & Boaz, 2003; Givon et al., 2004; Pud et al., 2005); and Norway (Risberg et al., 1997). The

use of print media and the internet is also noted in a review of international literature on women's use of CAM during pregnancy (Adams et al., 2009).

The majority of the above studies suggest that between 20-30% of citizens use media as a source of information. These findings are also confirmed by studies which examine this issue across several EU countries (Anelli et al., 2002; Molassiotis et al., 2005a) and which note a figure of 25%.

Some exceptions to this general trend are found. For example, both Johnston et al. (2003) and Reid (2002) suggest that between 6% and 7% of participants in their studies informed themselves through media, while Bucker et al. (2008) in Germany note that 10% of their participants drew on the media and the internet as sources of information. Hermes et al. (2004) in a German study, on the other hand, note that 48% of those considering the use of medical hypnosis are informed by the media, particularly TV.

The use of the internet as a specific source of information about CAM is also noted in different EU countries. Generally though the use of the internet for this purpose is low, compared to print and broadcast media. Studies in the UK (Domoney et al., 2003; Shakeel et al., 2008b), Turkey (Er et al., 2008; Kav, 2009), Israel (Pud et al., 2005) and the EU as a whole (Molassiotis et al., 2005a) point towards a range of 5% to 8%. Some studies suggest lower figures (Domoney et al., 2003) or that the internet is not used at all (Er et al., 2008).

There are also some exceptions to the general trend of low internet use for accessing information about CAM; these exceptions indicate that different groups of citizens may have different needs concerning the use of various media to access information about CAM: 26% of the parents of children with inflammatory bowel disease in the UK use the internet to make themselves knowledgeable about CAM (Gerasimidis et al., 2008). Some biomedical professionals are reported to draw even more extensively on the internet: 49% of Italian oncology nurses draw on the internet (Zanini et al., 2008), and approximately 44% of Czech pharmacy students do so (Pokladnikova & Lie, 2008).

These findings of generally low internet use for gathering information about CAM resonate with a qualitative study from the UK. This study gives insight into how citizens may go about using diverse media (Box 4).

**Box 4: An exploration of citizens' use of diverse media in seeking information on CAM in the UK**

Evans et al.'s (2007b) UK study of male cancer patients' ways of seeking information on CAM highlights that books, leaflets and the media were generally more popular than the internet. The internet was rarely the first port of call for accessing information, but rather provided a means to investigate a CAM therapy mentioned by acquaintances, to order books or nutritional supplements, and to find a CAM provider via a professional organisation. By using different information sources these men attempted to evaluate the different information as part of making informed decisions of what might suit them best.

*CAM providers*

Citizens also draw on diverse CAM providers as information source, though little is known about this compared to other sources. In the UK, studies which address this issue point towards contrasting results: when purchasing a CAM product Holst et al. (2009b) note that 6% of their participants followed information from a CAM provider while 20% of Reid's (2002) participants did so, and for some non-users of complementary therapies (28%) the most popular source of information about complementary therapy use are complementary therapy providers (Wilkinson et al., 2008).

Citizens may also seek information through specialist healthcare centres. Exploring the use of an integrated NHS cancer centre in the UK, Gage et al. (2009) draw attention to the importance of the centre in providing information: just over 40% of study participants used the centre to collect information about cancer or CAM. The study's authors note that this finding does not shed light on how many participants may have used the centre to gather information about CAM only.

Some detail on the role of CAM providers in offering information about CAM is also available for other EU countries. In Israel, 19% of study participants report that the use of homeopathy and/or naturopathy was recommended to them by homeopaths and naturopaths (Hana et al., 2005). In general terms, the relative insignificance of CAM providers as sources of information is mentioned by Bucker et al. (2008) for Germany and Kristof et al. (1998) for Switzerland, while Molassiotis et al. (2006a; 2006b) suggest that for Europe as a whole about 25% of CAM users with particular forms of cancer draw on CAM providers as information source.

	Sources of information			
	Country and author	Social network (sn) and self-initiated (si)	Biomedical professionals	Media and internet
<b>Cluster 1: social networks as main information sources about CAM</b>	<b>UK</b>			
	Artus et al. (2007)	47% (sn)		
	Emslie et al. (1996)	58% (sn)	28% biomedical professionals	
	Thomas et al. (2004)	59% (sn)	18% biomedical professional	
	Shakeel et al. (2008a/b)	62% (sn)	26% biomedical professionals	27% broadcast media; 5% internet
	Cinnotta et al. (2006)	74% (sn and si)		
	Crawford et al. (2006)	74% (sn and si)		
	Featherstone et al. (2003)		10% biomedical professionals	
	Sharples et al. (2003)	majority	18% biomedical professionals	
	Holst et al. (2009b)	'most used' (sn)	15% GPs; 3% hospital doctors 21% biomedical professionals (GP, midwife, nurse, pharmacist)	
<b>Turkey</b>				
Kav (2009)	46%		16% print media; 16% broadcast media; 5% internet	
<b>Israel</b>				
Hana et al. (2005)	41%	16%		
<b>Cluster 2: Biomedical professionals as main information sources about CAM</b>	<b>Germany</b>			
	Nagel et al. (2004)	32% (sn)	60 % GPs; 4% pharmacists	34% various media
	Joos et al. (2006)		40% GPs; 29% gastroenterologist; 15% other clinician	
	<b>But:</b>			
	Hartel et al. (2004)	Herbal remedies: 63% (si)		
	<b>Italy</b>			
	Gianelli et al. (2007)		58% GPs	
<b>But:</b>				
Dello Buono et al. (2001)	Acupuncture: 57% (sn and si)	42% GPs		
	Relaxation: 104% (sic) (sn and si)	18% GPs 4% specialists		
Pomposelli et al. (2008)	43% (sn)	32% Specialists and various media		

Table 2: Citizens' information sources (based on articles evaluated as high quality reporting)

### 3.1.2 Citizens' disclosure of CAM use to biomedical professionals

Citizens not only seek information about CAM from diverse sources, but also provide information about their use of CAM to biomedical professionals. Drawing on the literature that explores issues of disclosure of CAM use in biomedical settings, the extent to which patients disclose or not disclose their use or interest in CAM, together with their reasons for non-disclosure, is examined in this section.

#### *The extent of CAM use disclosure to biomedical professionals*

A considerable number of studies with a range of different groups of research participants provide information about the extent to which patients disclose or not disclose their interest in and use of CAM to biomedical professionals.

In the UK, non-disclosure to biomedical professionals ranges from 42% to 66% of study participants (Cincotta et al., 2006; Crawford et al., 2006; Emslie et al., 2002; Featherstone et al., 2003; Robinson et al., 2008; Shakeel et al., 2008b; Shakeel et al., 2008a; Shaw et al., 2008; Thomas & Coleman, 2004; Wilkinson et al., 2008). The majority of studies cite figures of around 50% to 60% of non-disclosure (and conversely 40%-50% of disclosure) (Emslie et al., 2002; Robinson et al., 2008; Shakeel et al., 2008b; Shakeel et al., 2008a; Shaw et al., 2008; Thomas & Coleman, 2004).

Variations of disclosure rates according to different groups of biomedical professionals with whom citizens engage with are also noted, though no clear trend can be identified: Corner et al. (2009) with respect to disclosure of CAM use by cancer patients note that 18% had informed their GP, 33% had informed their hospital specialist and 48% had informed a nurse (see also, Downer et al., 1994). A contrasting trend to who users might disclose their CAM use emerges from Wilkinson et al.'s (2008) study of men with cancer: 41% had informed their GP, 23% an urologist, and 21% an oncologist.

Rates concerning the disclosure of CAM use in other EU countries vary considerably, with trends of relatively high disclosure in Switzerland and Germany, medium disclosure in Israel, and low disclosure in Turkey and Ireland. Like their UK counterparts, citizens give largely similar reasons for non-disclosure in these countries.

The highest rates of disclosure are noted in Switzerland with between 50% -79% of study participants mentioning their CAM use to biomedical professionals (Quattropiani et al., 2003; van der Weg & Streuli, 2003; Zuzak et al., 2009). In Germany, 54% of those patients who received CAM not by their GP informed their biomedical professional of their CAM use (Joos et al., 2006) and 71% generally informed their GP about use of CAM (Laengler et al., 2008).

In Israel, around and just over 50% of CAM users do not discuss CAM use with their physicians (Ben-Arye et al., 2003; Hana et al., 2005). Thus, this Israeli sample closely

resembles UK findings. Nevertheless, 70% of Israeli participants in Giveon et al.'s (2004) study agree that they should disclose their CAM use to biomedical professionals.

The lowest rates of disclosure are noted for Ireland and Turkey. In Ireland, reported disclosure of complementary therapy use to GPs and hospital doctors ranges from 25%-54% of different samples of patients (Low et al., 2008; Murphy et al., 2008), while in Turkey between 13% and 31% of study participants inform their biomedical healthcare provider of their CAM use.

These studies point towards a spectrum of disclosure rates of general CAM use in different EU countries that ranges from low disclosure where the majority of CAM users do not discuss CAM with biomedical professionals to high disclosure where the majority do disclose their use of CAM (see Figure 1). Countries in which CAM is often practised by biomedical professionals and where its practice is highly regulated appear having higher disclosure rates.

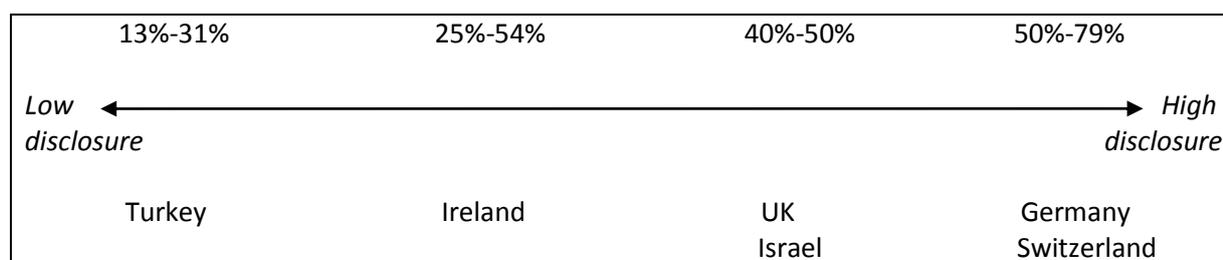


Figure 1: Citizens' disclosure of CAM use to biomedical professionals

In addition, some studies specifically examine how many citizens disclose/not disclose the use of herbal medicines. Figures for non-disclosure of herbal use to biomedical professionals in different studies in EU countries range from 55% to almost 90% of study participants and therefore largely confirm the above pattern of disclosure. For instance: between 74% and 87% of participants in Turkey (Kara, 2009); 76% of women in a UK study (Holst et al., 2009b); 58% in Italy (Bacchini et al., 2008; Cuzzolin & Benoni, 2009); and 55% of a sample in Israel (Giveon et al., 2004) do not disclose their use of herbs to biomedical professionals.

#### ***Citizens' reasons for non-disclosure of CAM use to biomedical professionals***

A systematic review of international literature concerning the disclosure of CAM use to biomedical professionals (Robinson & McGrail, 2004) identified three main reasons for citizens' non-disclosure:

- Experiences of or concerns about a negative response from biomedical professionals
- The perception that biomedical professionals did not need to know
- The fact that biomedical professionals did not ask

These reasons also emerge as being critical in the studies included in this present overview, with slight variations being noted in different countries.

Citizens' in the UK stated main reasons for not disclosing CAM use are: they perceive it not to be important for biomedical professionals to know about their use of CAM (Gerasimidis et al., 2008) and that biomedical professionals had not asked them (Wilkinson et al., 2008). Citizens' experience of not being asked is confirmed by Fountain-Polley et al. (2007) who report that 31% of hospital specialists and 14% of GPs routinely ask their patients about CAM (see also Box 5).

**Box 5: Citizens' non-disclosure of CAM use to biomedical professionals: insights from qualitative studies**

Several qualitative studies which explore citizens' reasons for not disclosing their CAM use to biomedical professionals point towards biomedicine's concern about the legitimacy of using CAM (Badone, 2008; Evans et al., 2007b; Green et al., 2006; Holst et al., 2009a; Tovey & Broom, 2007). These studies highlight that the concealment of CAM maybe a strategy to foreclose a negative response from biomedical professionals. In disguising their use of CAM, citizens may, for instance, aim to evade conflict during consultations or avoid provoking anger of biomedical professionals, and/or for their use of CAM to be interpreted as disloyalty leading to a declining sense of obligation to the patient (Badone, 2008; Green et al., 2006; Paterson & Britten, 1999; Stevenson et al., 2003).

Citizens may also position CAM use as not affecting any biomedical treatment, and hence not needing to be discussed in biomedical consultations, since it has other aims, such as supporting the immune systems (Stevenson et al., 2003). Whatever CAM users' reason for not disclosing their use of CAM, a sense of an 'illicit' and 'underground' nature of CAM use (Holst et al., 2009a) emerges.

On the other hand, if biomedical professionals do not seem interested in patients' use of CAM, then patients may not believe this information to be relevant (Stevenson et al., 2003). At the same time, Stevenson et al. (2003) argue, if GPs do not perceive of themselves as knowledgeable about CAM, they are not likely either to discuss it or encourage discussion about it (see also, Crawford et al., 2006).

Citizens in other EU countries also cite not being asked by biomedical professionals as their main reason for not declaring their CAM use (Kara, 2009; Murphy et al., 2008) and/or think it unimportant for biomedical professionals to know about CAM use (Giveon et al., 2004; Murphy et al., 2008). In addition, fear of not receiving biomedical treatment as a result of CAM use, embarrassment, and anticipated anger of biomedical professionals about CAM therapy use are also mentioned in studies from Turkey and Ireland (Arykan et al., 2009; Murphy et al., 2008).

Citizens' perceived lack of interest in their CAM use may also be reflected in another aspect related to information provision or sharing: the lack of recording CAM use in (biomedical) patient notes. Cincotta (2006) and Crawford (2006) in their sample in a UK children's hospital in-patient notes report that even though CAM use might have been discussed

during consultations, it was not recorded in patients' notes. Thus biomedical practitioners may have difficulty accommodating pluralism in medical use due to ignorance rather than hostility (Stevenson et al., 2003; see also Ozcakir et al. 2007).

### 3.1.3 Citizens' needs regarding information about CAM

Emerging from the diverse studies that address issues of information about CAM is a multi-dimensional decision-making environment in which the availability of information plays a central role (see Box 6).

<b>Box 6: The importance of CAM information: a UK user's perspective</b>
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A participant in Evans et al.'s (2007a: 3) study of men with cancer links the availability of information not only with disease management but also empowerment and decision-making. He comments: 'I just think that information should be out there for people to make decisions and to let them know that it's there.'
--

In this decision-making environment, the absence of information on CAM is also reflected in citizens' decisions not to be using CAM. Indeed, the lack of information about CAM, including lack of knowledge about efficacy and/or safety for use in specific situations (Adams et al., 2009; Badger & Nolan, 2007; Corner et al., 2009; Laengler et al., 2008; Molassiotis & Cubbin, 2004; Rossi et al., 2005), is often cited by citizens as the main reason for their non-use of CAM (see for example Box 7).

Studies from the UK (Lewith & Chan, 2002b; Wilkinson et al., 2008), Germany (Junker et al., 2004; Laengler et al., 2008), and Italy (Rossi et al., 2005) report that between 33% and 48% of study participants did not use CAM as a result of lack of information about CAM. These findings support the conclusion from Germany and Turkey that the more information individuals have about CAM the higher CAM use (Araz et al., 2009; Eustachi et al., 2009).

This trend concerning reasons for non-use of CAM is however not supported by Molassiotis et al.'s (2005a) EU study of cancer patients; here only 2% of participants reported not to use CAM as a result of lack of information. Similarly in Pud et al.'s (2005) Israeli study 7% of participants gave lack of information about CAM as their reason for non-use; however, an additional 39% reported that they had never considered the use of CAM.

**Box 7: Attitudes to seeking information: an example from the UK**

The male cancer patients in Evans et al.'s (2007b) study cited the lack of knowledge and information about CAM as a major reason for non-use, and CAM users and non-users alike reiterated the need for information and advice through the NHS. At a minimum many of the participants wanted the NHS to provide CAM information about resources and providers and the majority of participants wanted a 'stamp of approval' from NHS professionals regarding CAM therapies. Many also mentioned the hope and expectation that CAM information would be easily accessible within the NHS and expressed disappointment when this was not the case.

These findings point towards citizens' need for trustworthy information provision about CAM, both in the form of 'signposting' to CAM providers or resources and the offering a 'stamp of approval' regarding CAM use. Other participants in the same study however preferred to look outside the NHS for CAM information, aiming to seek 'alternative' philosophical and therapeutic approaches to their illness and its treatment.

### 3.1.4 Summary and conclusion

Citizens across various EU countries follow two broad patterns when gathering information about CAM, though variations exist between countries and also in each country, and the pattern identified here may not always be clear cut.

- In countries such as the UK, Turkey, Israel, Norway and Ireland, citizens' personal social networks constitute their main source of information about CAM, together with a relative lesser importance of gathering information from biomedical professionals
- In countries such as Germany and Italy biomedical professionals constitute a key source of information about CAM, while social networks tend to be relatively less important

In addition, and cutting across the above two patterns, the following can be observed:

- Citizens' personal experience with CAM informs their decisions about its future use, as well as the recommendation of CAM through social networks and in professional contexts.
- Irrespective of the above sources of information, citizens also draw on print and broadcast media to inform themselves about CAM; the internet as information source of CAM is generally limited, though this may have changed in more recent years.
- Little is known about the role of CAM providers (and their associations) as sources of information and as yet no clear picture can be identified. However, when compared to either the importance of social networks or biomedical professionals, CAM providers (and their associations) appear to be relatively insignificant information sources.

- Many citizens wish to gather information about CAM from biomedical professionals, even if they may not currently draw on biomedical professionals as a source of information.

A link between the availability of information about CAM and citizens' non-use of CAM is noted in the majority of studies which examine citizens' reasons for not using CAM. This highlights the significance of accessible, reliable and trustworthy information and knowledge about CAM in enabling citizens' to make informed choices about their healthcare.

The extent of citizens' disclosure of interest in or use of CAM to biomedical professionals reveals a broad spectrum of disclosure rates in different EU countries, which ranges from a majority of citizens in some countries (e.g. Germany and Switzerland) to a large minority of citizens in others (e.g. Turkey) disclosing their use of CAM to biomedical professionals. This may be a sign of possible correlations between:

- The extent to which CAM is practised by biomedical professionals and citizens' disclosure of their interest in and use of CAM, as noted for instance for Switzerland
- Citizens' disclosure of interest in and use of CAM and the attitudes to CAM held by different groups of biomedical professionals

Citizens' reasons for their non-disclosure of CAM include:

- Concerns about a negative response from biomedical professionals
- Not considering CAM use of importance in relation to biomedicine
- Not being asked about CAM by biomedical professionals

In sum, the reviewed literature of citizens' attitudes and needs regarding information about CAM reveals a multi-dimensional decision-making environment in which both citizens' attitudes and their needs are embedded. Together, these studies emphasise the importance of the availability of reliable and trustworthy information about CAM - however reliability and trustworthiness might be understood by citizens - to their making informed decisions about its use or non-use. Furthermore, citizens' disclosure of CAM use points towards the influence of biomedical attitudes to CAM in supporting or limiting the extent of discussion of CAM in biomedical encounters.

On the basis of the literature reviewed, the following gaps in knowledge concerning citizens' attitudes and needs concerning information about CAM can be noted:

- What precisely citizens' information needs about CAM are (such as the content and type of information required, preferences for different media)
- How different groups of citizens (and in different EU countries) access and use information about CAM, individual CAM modalities, and/or CAM medicinal products
- The role of CAM providers (and their associations) as information source

- The role of staff in pharmacies, health-food shops or chemists in providing information about CAM, particularly about CAM medicinal products
- How existing CAM research evidence can be disseminated more effectively
- How disclosure of CAM use to biomedical professionals plays out for different groups of citizens and/or different professionals; in relation to different CAM modalities and/or products; and in a range of EU countries with different kinds of CAM provision and regulations

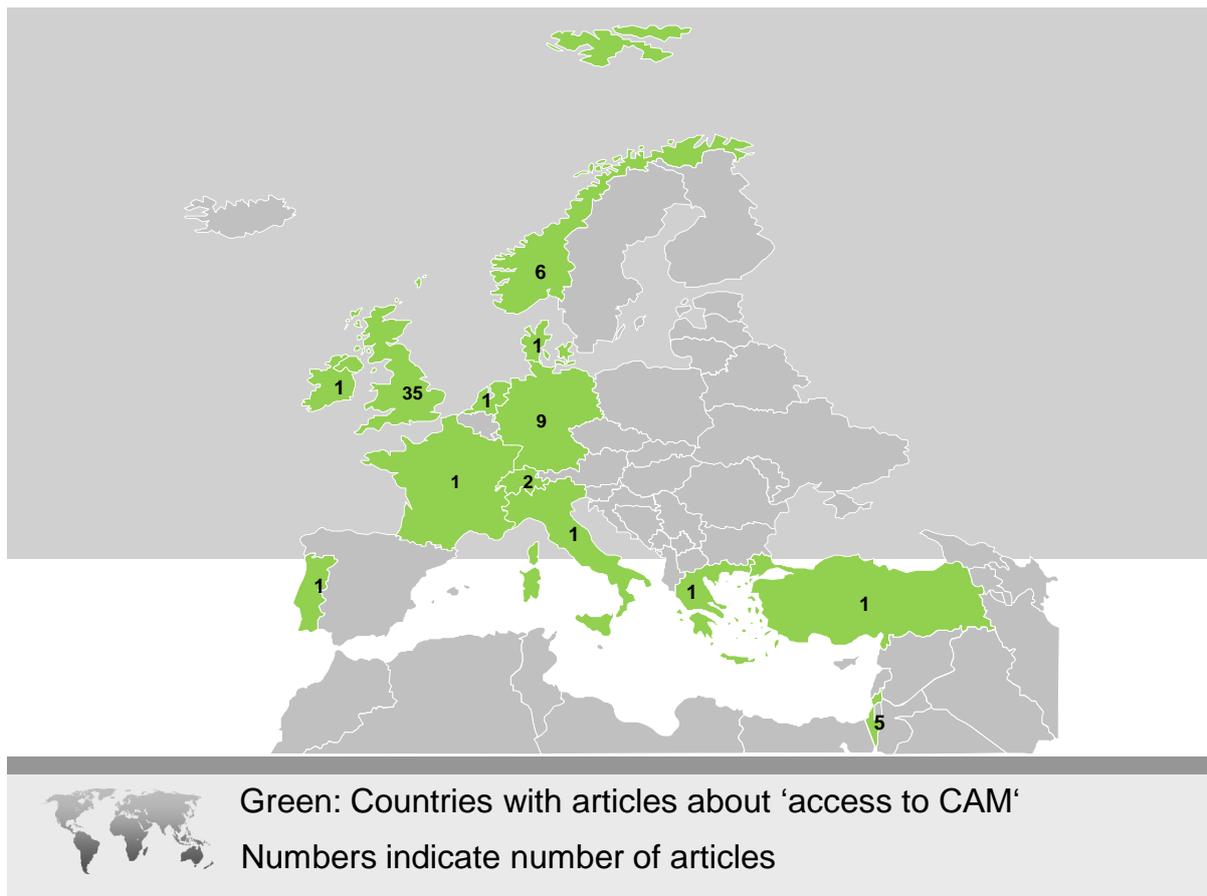
### **3.2 Citizens' attitudes and needs concerning 'access to CAM'**

Three broad themes emerge from the identified literature that examines citizens' attitudes and needs regarding 'access to CAM':

- Citizens' demand and support for CAM and CAM provision in public healthcare systems
- Barriers to CAM use and provision
- Citizens' choices and priorities when accessing and using CAM

This body of literature clearly demonstrates that citizens across a number of EU countries favour increasing CAM provision and its provision in public healthcare systems, together with a diversity of CAM provision. Citizens are also shown to experience practical and attitudinal barriers that limit their access to and use of CAM. The importance of increasing research into CAM as a way of supporting increasing CAM provision is recognised by citizens and health professionals alike.

Approximately 64 articles were identified which address issues relating to the topic of 'access to CAM' (see Map 3). These include articles which report on studies in individual countries as well as EU-wide studies.



Map 3: Countries with articles which address issues about 'access to CAM'

### 3.2.1 Demand and support for CAM and CAM inclusion in public healthcare systems

Citizens, often a large majority, in various EU countries express demand and support for the provision of CAM or of particular therapies in public healthcare systems.

In the UK context, several quantitative studies show that a majority of primary healthcare users (54%-66%) support the provision of CAM in the National Health Service (Emslie et al., 1996; Emslie et al., 2002; Johnston et al., 2003). Participants in qualitative studies echo these findings (e.g. Richardson, 2004; Shaw et al., 2006b).

Studies by Emslie and colleagues provide details about citizens' support for particular therapies to be provided in the National Health Service (NHS), and how such support has changed over time: in 1993, 54% of primary health care users thought that acupuncture and 50% thought that osteopathy should be available in the NHS (Emslie et al., 1996). The follow up study shows that increasingly more people support the provision of CAM in the NHS, particularly of chiropractic (38% in 1993 to 51% in 1999) and reflexology (29% in 1993 to 42% in 1999) (Emslie et al., 2002).

From the perspective of biomedical professionals in the UK, the support for increasing CAM provision in the NHS is also noted: White et al. (1997) note that 55% of GPs support the NHS funding of chiropractic, acupuncture and osteopathy, and heads of maternity services are said to be generally positive about increasing integration of CAM into maternity provision (Williams & Mitchell, 2007). Both citizens and biomedical professionals in the UK hence generally support the NHS provision of CAM and/or of specific therapies in particular, notably chiropractic, osteopathy and acupuncture.

In Israel, too, the support for the inclusion of CAM services into the public healthcare system is noted: both women and men (96.6% and 94.4% respectively) and Arabs and Jews (82% and 83% respectively) favour the inclusion of CAM services into public healthcare (Ben-Arye et al., 2009a; Ben-Arye et al., 2009b) and most patients expect to receive CAM in primary care settings (Ben-Arye et al., 2008). Yet few Israeli doctors cooperate with CAM providers, with 70% of hospital doctors not referring patients to CAM clinics (Fadlon et al., 2008)

In Norway, explorations of the integration of CAM have focused in particular on the availability of CAM in hospitals for the treatment of cancer patients and the identified articles offer contrasting result: 63% of general practice patients in Norway felt that CAM should be an option for cancer patients in hospitals; in the group of cancer patients themselves 43% thought so (Risberg et al., 1997; Risberg et al., 1995), including spiritual or faith healing frequently used by cancer patients (Risberg et al., 1996). These findings contrast with a more recent study, which suggest that 5% of a general population thought that GPs should recommend acupuncture for cancer patients (Norheim & Fonnebo, 2000). Among oncology healthcare professionals variations are also noted: Only few physicians (4%) consider alternative medicine positively, compared to 33% of nurses and 32% of radiographers; women showed a more positive attitude than men (33% and 14%, respectively) (Risberg et al., 2004). Another Norwegian study examines a different issue, namely the inclusion of traditional healing methods into mental health services in Sami areas; the majority (81%) of respondents in this study supports its inclusion (Sexton & Sorlie, 2009).

From the perspective of physicians in Italy, Switzerland and Israel, research highlights that physicians experience a high preference for CAM among their patients. For example, 76% of physicians in the province of Parma (Italy) claim that their patients want to use CAM (Cocconi et al., 2006). A Swiss study states that patients regularly request CAM treatments: 30% of physicians claim that they are asked more than once/week, 20% are asked once/week and 50% less than once/week (Deglon-Fischer et al., 2009). Likewise in Israel, where, according to Bernstein et al. (1997), most doctors refer patients for CAM treatment, frequently at the request of patients.

The patients' perspective also reflects this trend: nearly 70% of German primary care patients would like to be treated more frequently with CAM, especially by their GP, and 58% prefer CAM to biomedical treatment (Himmel et al., 1993).

### 3.2.2 Barriers to CAM use

Multiple barriers to the access and use of CAM are noted in the literature on citizens' attitudes and needs to CAM. These include:

- Practical barriers to CAM
- Attitudes of biomedical healthcare professionals to CAM
- Lack of information and knowledge about CAM

The first two issues are the main focus of this section. Several issues concerning the lack of information and knowledge about CAM have been explored in the previous section, and further related aspects will be considered in the broader context of citizens' needs regarding access to CAM.

#### *Practical barriers to CAM use*

Two main practical barriers to accessing CAM can be noted: the cost of CAM, and the geographical proximity of CAM provision. These are examined in turn.

##### *The cost of CAM*

A considerable barrier to citizens' access to CAM is the cost of CAM treatments paid for out-of-pocket. Some related issues appear to differ depending on whether CAM is provided largely in the private sector or where CAM treatment expenses are covered by health insurance schemes. These will be explored in turn, followed by issues that cut across the different payment systems that exist in different EU countries.

The UK serves as an example where *CAM is predominantly provided in the private sector* and users have to cover the cost entirely by themselves (Thomas et al., 2001a). A number of studies have examined issues relating to citizens' access to CAM, which highlight several associated aspects, some of which result in contrasting findings:

- Citizens' willingness to pay for CAM treatments
- Citizens' demands for NHS funding of CAM or particular CAM therapies
- Cost as a barrier to accessing CAM

Emslie et al. (1996) report that 57% of respondents were willing to pay or pay towards the cost of CAM treatments. Those who had used CAM therapies were more likely to be willing to pay than those who had not (83% and 70% respectively). The provision of acupuncture and osteopathy in the public healthcare system was particularly supported (54% and 50% respectively).

These findings, to some extent, resonate with Bishop et al.'s (2008) qualitative study in which participants come to similar conclusions concerning the NHS funding of particular CAM therapies such as osteopathy (see Box 8).

**Box 8: Who should pay for CAM use? Perspectives from the UK**

Bishop et al. (2008) argue that her participants present a rationale for who should pay for CAM treatment, according to whether a CAM therapy is perceived as a 'treat' or 'treatment'. Therapies are categorised as a 'treat' when they were described as pleasant experiences used for personal enjoyment; included here are particularly aromatherapy massage and reflexology. As a luxury commodity they should be paid for personally. 'Treatments' by contrast prevent, relieve, or cure a specific health-related need, and include osteopathy, herbal medicine and homeopathy. These treatments should be state funded.

Participants in a study on CAM cancer care support the above overall finding that a majority of patients (76%) are prepared to pay for treatment (Lewith et al., 2002a). The same study however does not support Emslie et al.'s (1996) or Bishop et al.'s (2008) findings concerning which CAM therapies should be state funded. Participants in Lewith et al.'s (2002a) study supported the inclusion into the NHS of the five most popular treatments provided for cancer in this study, namely: massage, nutrition, aromatherapy, and reflexology. These differences between the studies may reflect the different health needs of the participants and of how different groups of citizens use CAM to address those needs.

Several qualitative studies correlate free access to CAM with its uptake and highlight that the provision of CAM in the UK private sector may prevent some citizens or particular groups of citizens from using CAM. Corner et al. (2009) argue that the free provision of CAM encouraged some patients to consider its use (see also Mercer & Reilly, 2004). Affordability was also shown to be a key issue for older people (Cartwright, 2007), Chinese migrant women in England (Green et al., 2006), asthma patients (Shaw et al., 2006a), acupuncture users (Freedman & Richardson, 2005), and users of osteopathy and chiropractic (Ong et al., 2004).

In Israel and Denmark, like the UK, CAM is largely provided in the private sector and issues concerning the cost of CAM treatments have been examined. Israeli citizens are shown not only to support the inclusion of CAM into the national healthcare system but would also be willing to pay for CAM services, particularly women (women: 75.9%; men: 72%) (Ben-Arye et al., 2009a). In Denmark on the other hand, the cost of CAM may constitute a barrier to its use, as suggested by la Cour (2008).

Explorations of *reimbursement of CAM treatments through health insurance schemes*, such as in Germany and Switzerland, reveal a complex picture with financial and other implications for citizens' access to CAM treatment. For the case of Germany, Schwarz et al. (2008) note that while all CAM therapies used by their participants were mostly prescribed by physicians, full or partial reimbursement differed according to therapy. A majority (73%) of patients with inflammatory bowel disease receiving CAM also reports that they financed their CAM treatment in part or completely themselves (Joos et al., 2006). This led most

participants (96%) to call for CAM treatments to be reimbursed through the statutory health insurance (Joos et al., 2006). This call for CAM reimbursement through statutory insurance however is not supported by findings from Freivogel et al.'s (2001) study: 77% of their respondents were prepared to part-pay for CAM treatments, 13% were willing to completely pay for CAM, and 8% were not prepared to do so.

Variable reimbursement, and consequently out-of-pocket expenses for CAM treatments, also has implications for the treatment choices that citizens' may make: 45% of Swiss respondents prefer to use those CAM therapies that will be reimbursed. Finally, citizens' willingness to purchase additional insurance cover for CAM expenses has also been examined: Härtel et al. (2004) note that only 4% of German respondents were willing to do so, with an additional 30% being possibly willing and 50% rejecting the suggestion. However, 16% of respondents already had a private insurance which covers CAM treatment.

As noted, irrespective of the different contexts for covering the financial cost of CAM treatments many citizens in Europe find themselves in a position of having to pay for their CAM treatments of choice, leading to differential access to CAM by diverse groups of citizens. In addition, both Thomas et al. (2004) and Schwarz et al. (2008) observe a low utilisation of CAM in particular regions of the UK and Germany (the north of England and West Pomerania, respectively). For West Pomerania, Schwarz et al. (2008) suggest, that this may be the result of limited financial resources prohibiting extra payment for CAM despite interest in CAM use in this Eastern area of Germany (previously part of the German Democratic Republic). This explanation may also apply to Thomas et al.'s (2004) findings, as the north of England is considerably less affluent than the south.

These conclusions however are not fully supported across all EU countries. A European survey of cancer patients shows that only 1.7% of respondents from various EU countries cited the inability to pay for CAM as a reason for its non-use (Molassiotis et al., 2005a). Likewise, participants in a small study from Portugal perceive CAM therapies as not expensive, but nevertheless feel that it should be subsidised by the government (Nunes & Esteves, 2006). Similarly, a Turkish survey concludes that the low cost of CAM makes CAM particularly attractive to the unemployed (Erci, 2007).

Notwithstanding the possible and real financial barriers in accessing CAM that many citizens may encounter, the question still arises why so many CAM users are willing to pay privately for the CAM treatment of their choice. Badone's (2008) anthropological study in Brittany (France) offers significant insights into why this might be the case. This study highlights a notion of cost that is less concerned with financial burdens on citizens but with the physical and emotional consequences of biomedical treatment. Box 9 provides more detail.

**Box 9: Reasons for paying out-of-pocket for CAM treatment: a perspective from France**

One of the participants in Badone's (2008) French study describes the CAM healer she consults as not 'commercial', unlike her biomedical physician. Asked why she perceives the healer as less commercialised than biomedical doctors for whose services and medicines patients are reimbursed by national health insurance, the participant, according to Badone (2008: 198), explains that it is precisely because doctors' fees are reimbursed that they seek to profit from their treatments. In the participant's opinion, biomedical specialists exploit the health insurance system, by recommending costly and unnecessary tests and operations simply to provide more income for themselves and their colleagues. Although patients bear little of the financial cost of these interventions, the participant argued that the physical and emotional costs experienced by patients in terms human pain and suffering are high. Emerging here is thus a notion of cost that is concerned with the physical and emotional consequences experienced by patients as a result of biomedical interventions, rather than financial cost.

*The geographical proximity of CAM provision*

Little is known about the importance of the geographical proximity of CAM provision in relation to its uptake. Studies from Germany and the UK however indicate that convenient access is of importance to citizens, irrespective of the context of CAM provision (Frank & Stollberg, 2004a; Gage et al., 2009). These findings may reflect both the financial cost of travel as well as the efforts required in terms of time and energy to get to a CAM provider, especially at a time when feeling unwell (see Box 10).

**Box 10: The importance of the geographical proximity of CAM provision**

Gage et al.'s (2009) study from the UK shows that CAM therapy use was inversely related to distance between the cancer centre and users' homes; that is, increasing distance of residence to the cancer centre decreased the likelihood of being a frequent CAM user at the centre.

Frank and Stollberg's (2004a) study confirms this observation for German acupuncture patients: patients' most frequent reason for choosing a particular CAM provider was related to providers' convenient access and proximity to users' homes.

***Biomedical professionals' attitudes as barriers to citizens' use of CAM***

Citizens' perceptions and experiences of biomedical attitudes to CAM, as well as biomedical professionals' attitudes to CAM have been explored in a number of studies from the UK, Israel, Switzerland and Germany. While there seems to be agreement across different studies that citizens experience or perceive negativity from biomedical professionals about CAM use (see Section 3.1.2), here citizens' wishes concerning biomedical support for their use of CAM and biomedical professionals' attitudes to CAM and particular CAM therapies are examined.

*Citizens' demands for more support for their CAM use*

From the perspective of citizens', a majority of participants in studies from the UK note that they would like biomedical professionals to be more receptive to and knowledgeable about CAM. Between 69% and 86% of primary care patients in UK studies agree that doctors should be more supportive of people using CAM (Featherstone et al., 2003;

Gerasimidis et al., 2008), while 54% of a sample of hospital outpatients thought that doctors should be more knowledgeable about complementary medicine (Robinson et al., 2008). Qualitative studies by Holst et al. (2009a) and Shaw et al. (2006b) support these findings (see Box 11).

**Box 11: Citizens' expectations of biomedical professionals: an example from the UK**

Expectant mothers using herbal remedies expressed a desire for the NHS generally to be more open-minded about CAM and as a minimum, to accept their use of herbal products (Holst et al. 2009).

Likewise, the participants in Shaw et al.'s (2006b) study wished for more respect for their choice of CAM use, and in addition expected biomedical professionals to have greater knowledge about CAM than their patients, so as to be able to advise appropriately.

Similar findings are reported for Israel and Switzerland. Both Israeli women and men expected their family physician to be receptive to CAM (94.6% and 93.2% respectively) and provide them with information (Ben-Arye et al. 2009a). In Switzerland, all participants in a survey of complementary medicine users would like their GP to be conversant with complementary medicine and 91% wanted their GP to recommend complementary medicine techniques. In addition, 71% of these participants would also like their GPs to practise a complementary medicine technique and 87% believed that their GP should co-operate with complementary practitioners, though only 29% claimed that their GP in fact does so (Kristof et al., 1998).

Findings from these various EU countries highlight citizens' wish for more support and knowledge about CAM from biomedical professionals. As examined earlier in this report, citizens' perceived lack of support for their interest in and use of CAM, and the acknowledgement of CAM use in biomedical contexts may lead to non-disclosure of CAM to biomedical professionals, and may thus constitute a significant barrier to accessing or using CAM (see Section 3.1.2).

*Biomedical professionals' support of CAM*

Citizens' perceptions and experiences of biomedical attitudinal barriers to CAM are also reflected in biomedical professionals' actual attitudes to and support of CAM or particular CAM therapies. Some of these issues have already been mentioned in relation to biomedical professionals' attitudes to the provision of CAM therapies in public healthcare systems (see Section 3.2.1) and here the focus is on biomedical support of CAM in more general terms. It is worth noting that the identified studies are largely concerned with the attitudes of biomedical professionals to CAM therapies offered through CAM providers rather than with their attitudes to CAM medicinal products.

From the perspective of UK biomedical professionals a general trend of support for CAM in general and for individual CAM therapies can be noted, with between 55%-79% of biomedical professionals backing CAM treatments. According to White et al. (1997) 55% of GPs endorse or recommend CAM treatments, and believe that chiropractic, osteopathy, and acupuncture should be funded by the NHS (see also, Perry & Dowrick, 2000). This finding is largely supported by van Haselen et al. (2004) who report that 79% of GPs refer patients for acupuncture. By contrast, according to Perry et al. (2000) less than 20% of GPs support the inclusion of medical herbalism, aromatherapy and reflexology in the NHS (Sharples et al., 2003). Overall, doctors' referral for CAM in the NHS remains low (Sharples et al., 2003; Thomas et al., 2001b)

With regards to CAM in general in the UK, van Haselen et al. (2004) observe a gendered pattern amongst GPs, and also differences in preferences for particular CAM therapies according to groups of biomedical professionals. Women GPs in general more frequently refer for CAM treatment than male GPs, and more women GPs are said to refer to homeopathy than male GPs; non-GPs on the other hand refer more frequently to therapeutic or aromatherapy massage (60% of non-GPs; 16% of GPs).

Other biomedical professionals can also be said to support this trend. For example, Fewell et al. (2005) suggests that NHS staff' recommendations to patients to use CAM are higher than the availability of CAM in the practice area, and UK pharmacy students are said to support the availability of CAM products within the NHS (Freyman et al., 2006). Turkish student nurses, like their biomedical colleagues in the UK, also favour CAM provision within the public healthcare system (Uzun & Tan, 2004).

A similar picture of general support for CAM and support for particular CAM therapies is also noted for Germany. Fifty-one percent of GPs and specialists are said to be in favour of CAM, with physical therapy, phytomedicine, exercise, nutrition and diet, massage and relaxation being particularly valued; GPs are noted to be more inclined to use CAM than specialists (Stange et al., 2008) . Most respondents in Brinkhaus et al.'s (2005) study of decision-makers in German medical schools were in favour of integration of CAM into the public healthcare system, with 74% viewing CAM as adjunct to biomedicine; 31% had a negative opinion about CAM, 27% had a neutral opinion and 3% of respondents were unsure. Attitudes also varied with CAM modality, with osteopathy, acupuncture and naturopathy being viewed most positively (52%; 48%; 41% respectively).

This trend towards biomedical support for CAM is however not confirmed in all EU countries: for instance, less than 10% of Greek physicians are familiar with unconventional cancer therapies (Munstedt & von Georgi, 2005).

### 3.2.3 Accessing and using CAM: Citizens' choices and priorities

Consideration of the provision of CAM as part of public healthcare systems also raises issues about the diversity of CAM provision to be offered, in terms of CAM providers, CAM therapies and locations of CAM provision. From the perspective of citizens in the UK and Israel, citizens support patients' choice of provision (Holst et al., 2009a; Shaw et al., 2006b), including receiving CAM from physicians with CAM training and CAM providers without biomedical training (Ben-Arye et al., 2009a). Such diversity is also supported by 49% of UK primary healthcare workers (nurses and GPs) (van Haselen et al., 2004).

Issues of how citizens access CAM provision overlap with issues of how citizens ensure the safety and quality of CAM provision as well as the CAM information sources they draw on. Of particular relevance here is the importance of biomedical professionals as sources of information about CAM and the endorsement and legitimacy of CAM conferred via biomedicine which was examined in Section 3.1. Together, these aspects, it can be argued, present a form of 'gate-keeping' where access to CAM therapies approved by biomedical professionals is supported while utilisation of others is limited (Tovey et al. 2007).

Such gate-keeping can be observed in both UK and Israeli studies. A UK study notes that 49% of respondents would use CAM only if referred by a doctor, with this figure rising to 77% for people who had not used CAM in the past (Featherstone et al., 2003). This finding is supported by other studies: a UK qualitative study suggests that CAM would not have been used without biomedical referral (Corner et al., 2009). Similarly, many respondents in an Israeli study expect their GP to initiate a referral to CAM (Ben-Arye et al., 2009a). This expectation of referral to CAM services as well as information provision about CAM via GPs is also noted in a qualitative study from the UK (Shaw et al., 2006b). However, some UK patients prefer to look outside public healthcare systems for CAM providers as they may be seen to practise a more 'alternative' CAM (Evans et al. 2007) (see Box 7).

Explorations of the provision of CAM as part of public healthcare systems highlight broader issues concerning citizens' attitudes to CAM, particularly concerning the perceived role of CAM in healthcare. These issues link with the ongoing debates about the definitions and meanings of CAM. The articles identified in this review may reflect not only citizens' different attitudes but also the shaping of these attitudes in the context of the provision of CAM in particular countries.

Some German studies represent both citizens' and biomedical professionals' perspectives on this issue: Härtel et al. (2004) find that a considerable number of German citizens believed that CAM therapies are suitable for the prevention rather than the treatment of disease (men: 31%; women: 22%) and complement biomedical healthcare (men: 35%; women: 29%). This view is supported by Brinkhaus et al. (2005) who state that 74% of decision-makers in medical school consider CAM as adjunct to biomedicine.

These findings from Germany contrast with findings from a UK qualitative study, where participants are said to categorise different CAM therapies as either ‘treat’ or ‘treatment’ (Bishop et al., 2008); for details, see Box 12.

**Box 12: CAM therapies in the UK: ‘Treat’ or ‘treatment’**

According to Bishop et al. (2008), participants’ attitudes to different CAM therapies allows a categorisation of therapies as either ‘treat’ or ‘treatment’. CAM therapies which are used for general enjoyment and pampering are considered to be a ‘treat’ (e.g. aromatherapy and reflexology), while those therapies that are based on a holistic model of health and aim at improving symptoms or general health (e.g. osteopathy, herbal medicine, homeopathy) constitute ‘treatments’ and are thus perceived as alternative healthcare to biomedicine.

### 3.2.4 Citizens’ needs regarding access to CAM

Citizens’ demand and support for increased access to and integration of CAM in public healthcare systems is well established across a number of EU countries, as is citizens’ wish for biomedical professionals’ open-mindedness and increased knowledge about CAM. Some studies, particularly from the UK, also observe that CAM users value the independent use and provision of CAM outside of public healthcare systems (Evans et al., 2007a; van Haselen et al., 2004), and that this is associated by some with more ‘alternative’ philosophical approaches to CAM practice (Evans et al. 2007a). This highlights citizens’ call for the diversity of CAM provision to be available both within and outside of national health services, and to comprise both biomedical professionals practising CAM and CAM providers without biomedical training (Ben-Arye et al., 2009a; Cartwright, 2007; Holst et al., 2009a; van Haselen et al., 2004).

While calling for diversity of CAM provision, citizens are also aware of the lack of scientific evidence, knowledge and research into CAM and the need for scientific evaluation of CAM. This is noted in different studies across various EU countries, including the UK, Switzerland, the Netherlands, and Germany (for example, Joos et al., 2006; Kristof et al., 1998; Shaw et al., 2006a; Stronks et al. 1997; Wye et al., 2009). The lack of knowledge about CAM leads some citizens to suggest that CAM should not be provided through public healthcare services (Stronks et al. 1997) and others to call for more CAM research (Joos et al., 2006).

Furthermore, biomedical and CAM providers recognise the need for more research, particularly concerning clinical effectiveness, patient satisfaction, service evaluation and cost-effectiveness (Luff & Thomas, 2000b). This raises questions about CAM research and CAM provision which are grounded in notions of scientific evidence, quality and safety (see above and section on EU policy) and which may ‘fit’ biomedical healthcare (Tovey & Broom, 2007; Wearn & Greenfield, 1998; Wye et al., 2009). These scientific assessments may contrast with the ways in which citizens’ assess and understand these issues, with

what citizens value when using CAM (see Section 3.3), and with their needs for diversity of provision.

### 3.2.5 Summary and conclusion

Only few studies and from a limited range of EU countries, when compared to the availability of studies concerning information about CAM, have examined issues relating to citizens' access to CAM. Despite these limitations, the following overall trends regarding citizens' attitude and needs concerning CAM can be noted:

- The majority of citizens support and demand increasing access to CAM and the provision of CAM within public health services. Some of this support differs with regard to CAM therapies, possible user groups, and CAM providers
- Citizens call for a diversity of CAM provision, comprising a range of CAM therapies; the provision of CAM therapies within and outside of existing public health services; and by both biomedically trained providers and providers trained exclusively in CAM
- The cost of CAM constitutes a significant barrier to its use, as does citizens' perceived lack of biomedical support for and knowledge about CAM
- The majority of citizens would like biomedical professionals to be more supportive of and more knowledgeable about CAM, and also have a greater role in terms of referral to CAM and as sources of information. This indicates that biomedical attitudes to CAM may constitute an important barrier to accessing CAM.
- The attitudes of many biomedical professionals indicate, very generally speaking, support for CAM, particularly so for chiropractic, osteopathy and acupuncture and/or the use of CAM as an adjunct to biomedicine. Indications are however that this may not meet the experiences and needs of diverse groups of citizens concerning the types of CAM they may wish to use to address their health needs
- Citizens, like biomedical and CAM providers, recognise the need for more research into CAM and support its scientific evaluation

In sum, citizens' demand and support for CAM and CAM integration into public healthcare systems is well established in the literature reviewed here. This demand for increasing access to CAM through public health services links with some of the barriers to CAM use that citizens experience and/or perceive (such as its financial cost, biomedical professionals' attitudes to CAM, and their lack of openness and knowledge about CAM), as well as with citizens' need for a more active role of biomedical professionals in supporting their CAM use. The importance citizens attach to the research of CAM not only supports the availability of knowledge, but can also be seen as legitimising citizens' demands for CAM and for the diversity of CAM provision through increasing the recognition of CAM and/or particular CAM therapies.

On the basis of the literature reviewed, the following gaps in knowledge about citizens' access to CAM can be noted:

- How different citizens (and groups of citizens) access CAM and individual CAM modalities, and what motivates some people not to use CAM
- How attitudes to CAM held by various groups of biomedical professionals shape and influence citizens' utilisation of CAM and/or particular CAM therapies
- How citizens' processes of accessing CAM are related to an understanding of a notion of 'cost' beyond financial implications
- The existing diversity of CAM provision, comprising the range of CAM therapies; the provision of CAM therapies within and outside of public health services; and by both biomedically trained providers and providers trained exclusively in CAM
- Citizens' patterns of accessing CAM depending on a diversity of provision
- The cost-effectiveness of CAM provided in public healthcare systems
- The social implications of privately funded CAM treatments

### **3.3 Citizens' attitudes and needs concerning the 'quality of care' in CAM**

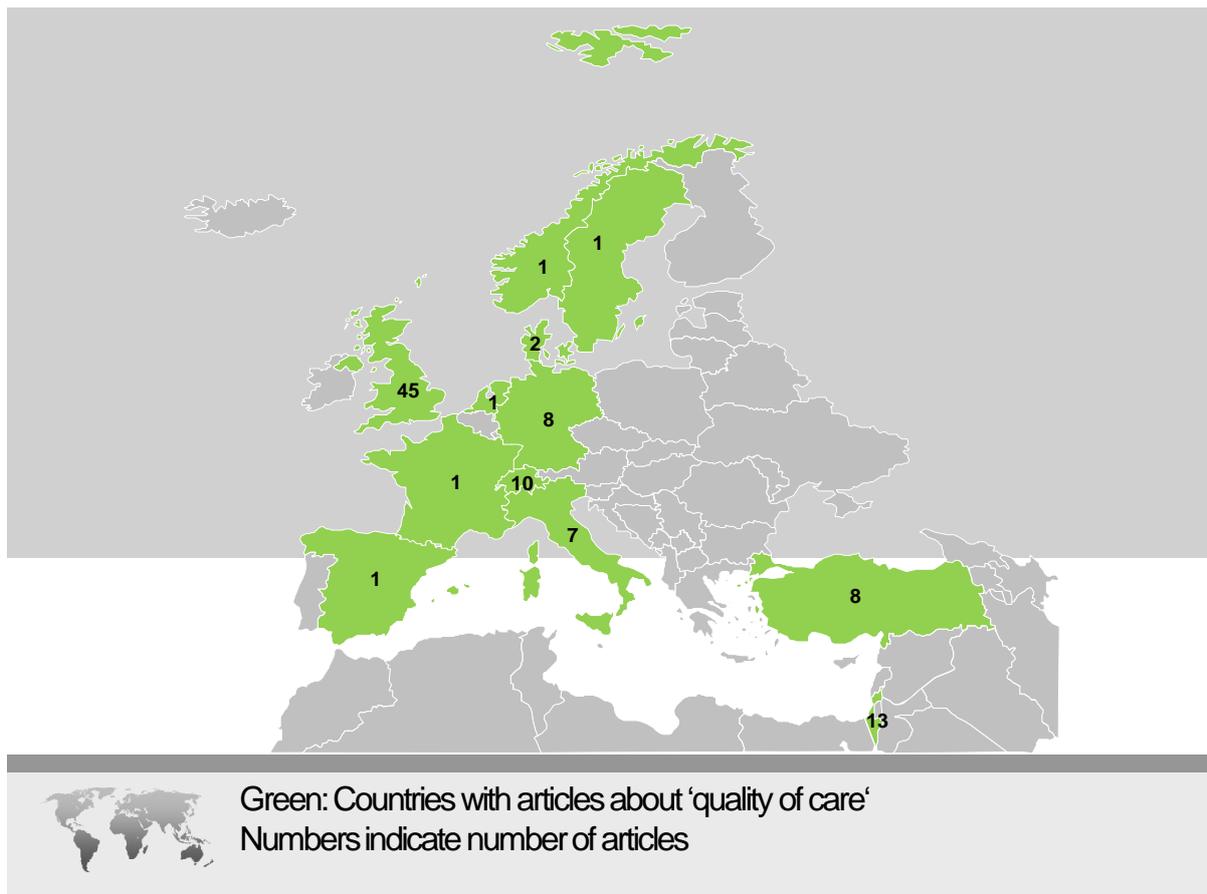
The literature that explores the topic of citizens' attitudes and needs regarding the quality of care in CAM points towards two main areas:

- Issues related to the practice of CAM, including the CAM provider-patient relationship and the explanatory frameworks provided by CAM
- Issues relating to the safety of CAM products and provision, including citizens' perception of CAM as 'natural', 'traditional' and safer than biomedicine, and citizens' diverse strategies to ensure the safety and quality of their CAM use

The combined consideration of these issues presents a broad picture concerning the quality of care in CAM.

Two key observations can be drawn from the exploration of this body of literature: Firstly, citizens value the patient-centred approach offered in CAM consultations, where they have a voice in negotiating treatment options and which may enable them to take control of their own care. Secondly, citizens draw on a number of explanations and strategies to consider and evaluate the safety and quality of CAM. In doing so, they are making meaningful decisions and establish priorities for their healthcare within their own frames of reference and value systems.

The literature searches have identified about 98 articles which address the topic of 'quality of care' in CAM (see Map 4). These articles report on studies in individual countries, EU-wide studies, and systematic reviews of literature.



Map 4: Countries with articles about 'quality of care' in CAM

### 3.3.1 The practice of CAM

The issues emerging from the identified literature concerning citizens' attitudes and needs regarding the practice of CAM can be grouped into two categories

- The CAM provider-patient relationship
- The holistic values underpinning the practice of CAM

Together, these two aspects are frequently seen by patients as central to 'being in control' and of person-centred care, reflecting both their needs and their attitudes to CAM practice.

#### *The CAM provider-patient relationship*

Many aspects shape and influence the CAM provider-patient relationship. Of these, two recurring themes emerge from the identified literature in relation to citizens' attitudes and needs concerning CAM. These are:

- Communication between CAM patients and providers
- Decision-making in CAM

A third theme concerns citizens' critiques of CAM practices. These themes are examined in turn.

#### *Communication between CAM patients and providers*

Communication stands out as a central theme in citizens' experience of healthcare in general and a positive provider-patient relationship in particular. In this context, the perception of having time for in-depth discussion, questions and explanations during CAM consultations is frequently mentioned.

Concerning the topic of 'time', research from Switzerland is most prominent, particularly in studies which evaluate users' experiences of communication with providers of different CAM therapies in comparison with their experiences in biomedical encounters (Esch et al., 2008; Marian et al., 2008; Matter-Walstra et al., 2008; Melzer et al., 2008). In these studies, between 71%-77% of patients particularly valued the time available during consultations, compared with 62% of those using biomedical care. Studies from Spain and Germany support this emphasis on increased time in CAM consultations (Garcia-Campayo & Sanz-Carrillo, 2000; Schneider et al., 2004), with 70% of participants in Spain also valuing the increased time available (Garcia-Campayo & Sanz-Carrillo, 2000).

Swiss CAM users closely link the time available in CAM consultations with the perceptions of 'being listened to' (Esch et al., 2008; Marian et al., 2008; Matter-Walstra et al., 2008; Melzer et al., 2008). Between 74%-80% of these Swiss patients valued being listened to by their CAM provider, compared to 67% of conventional care patients.

The findings from these diverse studies also resonate with Xing et al.'s (2006) retrospective survey undertaken at an Acupuncture Teaching Clinic in the UK. Nearly all participants (95%) 'strongly agreed' or 'agreed' that their practitioner listened and accepted them; 85% noted that they liked the treatment environment and nearly all (93-95%) said they felt relaxed and enjoyed the sessions. Accordingly, 74-95% of respondents indicated that they had developed a highly positive practitioner-patient relationship. Indeed, a positive CAM provider-patient relationship is described by Furnham et al. (1994) as an important 'pull' factor towards CAM.

The importance of communication, particularly the time for discussion in CAM consultations and the experience of being listened to by the CAM provider was also noted in a number of qualitative studies from the UK (Cartwright & Torr, 2005; Evans et al., 2007b; Little, 2009; Luff & Thomas, 2000a; Mercer & Reilly, 2004; Murray & Shepherd, 1993; Shaw et al., 2006a; Strutt et al., 2008), Denmark (la Cour, 2008) and France (Badone, 2008), and frequently contrasted by participants with a perceived lack of time available in biomedical care. Resonating with all these studies is Cartwright et al.'s (2005) assertion that 'having time and being heard' is central to the patient-provider relationship in CAM. In addition, different financial arrangements concerning the payment of CAM treatments are shown by Frank et al. (2002) to have important implications for the CAM provider-patient relationship (see Box 13).

**Box 13: CAM provider-patient relationships in light of economic pressures: a German study**

Frank et al. (2002) argue that while there is a certain degree of partnership in the relationship between patients and their physicians who provide homeopathy in Germany, they also note areas of tension and disagreement. Of these, they argue, the duration of the consultation is the most critical issue for those who provide homeopathy through the public health insurance system.

Within the system of public health insurance the economic pressure leads to shortened consultations and clashes with some patients' expectation of extensive care. In this context the physician/homeopathy provider–patient relationship is - in economic respects - a triad: Patients pay for their insurance which pays the fees of the physicians/homeopathy provider and influences their economic framework. The homeopathic physician–patient-interaction unfolds within this context and produces conflicts on the issue of 'time'. In private practice the relationship remains a dyad of homeopath and patient where the different institutional context enables a more generous time-frame during consultations.

Some qualitative studies emphasise not only the availability of increased time in CAM consultations, when compared to biomedical encounters, but also the quality of the time and the encounter (Badone, 2008; Luff & Thomas, 2000a; Mercer & Reilly, 2004; Murray & Shepherd, 1993; Shaw et al., 2006a). Central to the quality of CAM consultations, these studies suggest, is providers' empathy, compassion and the development of mutual trust. Different perspectives on trust in CAM practice are explored in Box 14.

**Box 14: Perspectives on trust and CAM practice**

A connection between being listened to and experiences of empathy is drawn in Badone's (2008) anthropological study in France in which the healer is described by one of his patients as 'human' who treats patients with empathy and concentrates on their problems; by contrast, biomedical professionals are perceived as cold and aloof and difficult to make human contact with. As a result, trust between patient and healer informs their relationship.

Similar to Badone's (2008) participant, male cancer patients in the UK also found it difficult to 'make a connection' with their clinicians. This, they suggest, leads to finding it hard to formulate and ask questions (Evans et al., 2007a; Evans et al., 2007b).

Trust also emerged as an important theme in Cartwright et al.'s (2005) UK study, whereby trust underpins a 'relationship of equals' and shapes an 'egalitarian "two-way" relationship'. In addition to being an important aspect of the CAM interaction, it also influenced participants' expectations about the provider-patient encounter and the role of the patient in decision-making processes.

Furthermore, patients' of Asian medicine suggest that trust in the CAM provider results from the individualised and patient-centred approach offered (Frank & Stollberg, 2004b). For patients at an osteopathic clinic in the UK, trust results from osteopaths' thoroughness, professionalism, and the effectiveness of treatment (Strutt et al., 2008).

A different perspective on trust comes from the Netherlands: Trust in future biomedical healthcare by chronically ill people, van den Brink-Muinen et al. (2006) suggest, is a significant predictor of CAM use, with the less trust citizens have in biomedical healthcare the more they will be inclined to use CAM.

*Decision-making in CAM*

A small number of studies highlight citizens' desire for active participation in their healthcare, particularly concerning the decision-making about their treatment and the implementation of treatment choices.

A UK study by Ratcliffe et al. (2002), which explores patients' preferences for characteristics associated with homeopathic and biomedical consultations in the UK, notes that most respondents expressed a preference for being in control of treatment decisions, with those receiving homeopathic treatment considering it 'very important' to be able to choose a course of treatment which they consider to be best for them. Likewise, some Swiss studies note that between 62%-68% of CAM participants in these studies want to be involved in making decisions about their healthcare, compared to 58% of patients using conventional care (Esch et al., 2008; Marian et al., 2008). The decision to be prescribing CAM may however also be made by a CAM provider who is a biomedical physician, without involvement of the patient (Schneider et al., 2004).

**Box 15: Decision-making in biomedicine and CAM: CAM user experiences from the UK**

Some participants in Evans et al.'s (2007b) UK study of men with cancer described a sense of passivity they experienced when accepting biomedical cancer treatment. The use of CAM, by contrast, enabled these men to make active choices, thus providing them with an avenue for self-help and a means of gaining a sense of control in the face of an uncertain future.

The potential to make decisions about their treatment, including the decision to stop using CAM, was also central to many older people in Cartwright et al.'s (2007) UK study, particularly for those participants with prior negative experiences of biomedicine.

*Citizens' critique of CAM practice*

In a very small body of mostly qualitative literature some critiques of CAM practice, which have been predominantly examined in the context of homeopathic practice, can be identified. These critiques focus on the provision of information about the CAM therapy in question, dissatisfaction with the CAM provider-patient relationship and frustration with the treatment situation as a whole. These studies highlight that citizens terminate treatment if they are dissatisfied with the treatment process and/or their relationship with the CAM provider. The issue of 'time' in consultations (see above) is also critical in this context.

Both Anelli et al. (2007) for homeopathy in the EU and Endrizzi et al. (2006) for homeopathy in Italy point towards users being dissatisfied with the level of information given to them about homeopathy as a therapy. This resonates with Frank et al.'s (2002) German study where it is noted that the relationship between homeopathy providers and patients is being strained around the lack of information patients perceive concerning the prescribing of homeopathic remedies. In addition, negotiations and disagreements

concerning patients' expectations, fees and the duration of consultations are noted (see Box 13, above).

Jorgensen et al. (2005) for Denmark, also identified dissatisfaction with homeopathic treatment by some patients, particularly around the following issues: differences between homeopath and patient concerning the ways of understanding illness; when little time is offered to patients; and when the treatment situation as a whole too closely resembles GP treatment. In these situations, patients are shown to end their homeopathic treatment. The issue of similarities between CAM and biomedical treatment and relationships as a reason for stopping CAM treatments is also noted by Fadlon (2004) in a study in Israel (see Box 16).

**Box 16: Reasons for discontinuing CAM treatment: an example from Israel**

Fadlon's (2004) study of an Israeli healthcare centre providing integrated CAM/biomedical care shows that patients discontinue CAM treatment for three main reasons:

- Similarities of CAM treatment with biomedical treatment, such as when being referred for biomedical diagnostic tests
- An unexpected 'foreignness' of CAM
- Lack of anticipated involvement and/or independence in decision-making concerning treatment options

Notwithstanding users' reasons for discontinuing with CAM treatments, Fadlon (2004: 2426) observes: 'The marked satisfaction with the way in which treatment was delivered could not compensate for lack of cure or alleviation of symptoms. The bottom line always dealt with [treatment] outcome'. This leads Fadlon to conclude that her participants were acting as consumers.

***The values underpinning the practice of CAM***

A small number of quantitative studies from the UK (Ratcliffe et al., 2002; Strutt et al., 2008; Thompson et al., 2007), Germany (Unkelbach & Abholz, 2006), Israel (DeKeyser et al., 2001) and Switzerland (Messerli-Rohrbach & Schar, 1999) mention that CAM patients appreciate the values underpinning CAM. The importance of being treated as a whole person and the holistic approach advocated by CAM are particularly noted. This emphasis may however not be specific to CAM as more than half of the participants in Unkelbach et al.'s (2006) study equally valued anthroposophical and biomedical concepts.

Like the participants in the above quantitative studies, participants in qualitative studies from the UK, Germany and Norway also stress their appreciation of the values underpinning CAM. The personalised care and patient-centred character of CAM provision is singled out (Bishop et al., 2008; Frank & Stollberg, 2004b; Paterson & Britten, 1999), as well as the holistic whole person approach (Mercer & Reilly, 2004; Paterson & Britten, 1999; Rise & Steinsbekk, 2009; Shaw et al., 2006a). In addition, participants value the participatory approach of CAM to healthcare that enables and supports their increased involvement and autonomy in their own care (Luff & Thomas, 2000a; Richardson, 2004; Shaw et al., 2006a).

**Box 17: The importance of personalised care in CAM: older people's experiences**

The experiences of older people using CAM in the UK highlight that they, like other CAM users, particularly value the highly personalised care with CAM (Cartwright, 2007). The empowering nature of the treatment and the possibility of receiving adequate explanations were seen to be related to reduced anxiety. Overall, 'the whole package of care was perceived as an important source of support and reassurance in contrast to the impersonal experiences of orthodox medicine' (Cartwright, 2007: 1692). An integral part of the 'package of care' in CAM is, according to Cartwright, the provision of explanatory frameworks.

Explanatory frameworks provided by CAM providers often constitute an integral part of the 'package of care' referred to by Cartwright (2007) above and can be central to the ways some CAM users may make sense of their illness and its treatment, as qualitative studies from the UK (Cartwright & Torr, 2005; Murray & Shepherd, 1993), Denmark (la Cour, 2008) and France (Badone, 2008) note. The complexity of creating meaning about illness and treatment experiences in CAM and its implication for citizens is examined in detail in Box 18.

**Box 18: Meaning-making in CAM encounters**

Cartwright et al. (2005) suggest that understanding causal mechanisms for illness, as well as how to maintain health was an important theme for all their UK participants. In providing explanatory frameworks, they argue, CAM helps to make sense 'of what seems a bit senseless' (Cartwright & Torr, 2005: 563), aiding participants' ability to deal with their complaints and manage their health.

Badone (2008) makes a similar observation. She quotes one of her French participants who describes how she obtained 'another way of seeing the illness and of seeing myself, or to reflect on my own case, to analyze myself' (2008: 199) by taking recourse to CAM.

Furthermore, the holistic approach central to CAM, Cartwright et al. (2005) suggest, provides 'deeper-level' explanations of health and illness that linked physical and psychological aspects of health and illness. In this way, CAM was perceived as able to address underlying problems rather than only presenting symptoms. The idea of links between different levels of the body was a persistent theme in their participants' accounts and was also reflected in perceptions of health as comprising physical, mental and social well-being.

Both Cartwright et al. (2005) and Badone (2008) note that the explanatory frameworks provided by CAM providers are often congruent with users' own models of the body, health and illness. Badone (2008) for instance suggests that a healer in her French study approaches health problems not as a series of isolated events, but traces them to the same source. In doing so, illnesses are interpreted as symptoms of an underlying condition which is addressed by the prescribed treatment. By linking symptoms and illness episodes to a deeper illness paradigm the healer renders all of a patient's illnesses intelligible (Badone, 2008: 202). At the same time, the image of the body as an integrated whole that is held by the healer's patients is respected and ideas of the less intrusive and non-disruptive nature of his treatments are reinforced.

Similar beliefs about the body, health and the nature of CAM treatments are held by Cartwright and Torr's (2005: 564) UK participants who maintain that health involves 'working in harmony with your body' and that CAM is more harmonious with the body than biomedicine (Cartwright, 2007).

### 3.3.2 The safety of CAM products and provision

A number of studies are concerned with safety issues relating to the use of CAM and/or CAM products. These highlight two main areas:

- Citizens' perceptions of the safety of CAM and their explanations thereof
- Citizens' strategies to ensure the safety and quality of CAM provision

This section examines these areas in turn.

#### *The safety of CAM and CAM products*

Several studies examine users' perceptions of the safety of CAM and CAM products. These studies show that many citizens across the EU perceive CAM and/or CAM products as 'natural' and therefore safe or safer than biomedical treatment, and/or as not involving risk and/or side-effects (for details see Table 3). Available figures for this assessment of CAM originate from studies with CAM users of diverse health complaints, and range from 27% of participants in an Italian study (Rossi et al., 2005), to 45%-51% in Switzerland (Messerli-Rohrbach & Schar, 1999; Quattropiani et al., 2003), about 50% in a UK study (Sharples et al., 2003), and 82% in Turkey (Arguder et al., 2009).

The perceived safety of CAM products, particularly herbal medicines, as safer than pharmaceuticals and/or biomedical treatment, has also been explored. Around 29%-36% of participants in studies in the UK (Lynch & Berry, 2007), Italy (Cuzzolin & Benoni, 2009), and Turkey (Aydin et al., 2008; Kav, 2009) perceive CAM products to be safer than biomedical drugs, whereas 56% of participants in an Israeli study do so (Giveon et al., 2004). This assessment of CAM products as safer than biomedical medicines is not to suggest that citizens are uncritical or not also doubtful as to their safety and/or efficacy, as noted in studies from Italy (Bacchini et al., 2008; Cuzzolin & Benoni, 2009) and the UK (Holst et al., 2009a; Rhodes et al., 2008).

The historical use of some CAM therapies is frequently put forward as an explanation for the assessment of CAM safety (see Box 19). Others value both the naturalness of traditional remedies and their compatibility with their religious beliefs (Nakar et al., 2001).

**Box 19: Citizens' explanations concerning the safety of CAM and CAM products: Contributions from qualitative research**

Women participants in Holst et al.'s (2009a) UK study consider herbal remedies to be *safer* than pharmaceutical preparations, rather than *safe*, highlighting that these users are aware that 'herbal' does not *per se* equate with 'safe'. One explanation put forward by these women for herbs being relatively safe is their use over a long period of time in history. Alongside the perception of the relative safety of herbs, they also acknowledge the lack of trial evidence or the poverty of trial quality concerning the safety of herbs, particularly in pregnancy.

The male cancer patients in Evans et al.'s (2007b) UK study also judge the quality (and also likely effectiveness) of a therapy, such as acupuncture and herbal medicine, by its long-standing history. In addition, participants were also more likely to view CAM therapies positively where there had been a family history of using CAM therapies or products over several generations (*ibid*). The perception of CAM treatments as both natural and traditional can also reflect a reaction against the experience of side-effects of biomedical drugs or interventions, together with the adoption of the belief that health involves working in harmony with one's body (Badone 2008; Cartwright and Torr 2005).

The importance attributed to the historical practice of some therapies resonates with Murray et al. (1993) who suggest that their participants regarded questions of efficacy and scientific research as secondary to the avoidance of unknown long-term dangers from modern medical interventions.

Citizens' perceptions of CAM as generally speaking safe are often confirmed and reinforced by their personal experience of the safety of treatments. Studies from the UK (Crawford et al., 2006; Macpherson et al., 2004), Israel (Hana et al., 2005), and Switzerland (Michlig et al., 2008), and those exploring several EU countries (Anelli et al., 2002; Molassiotis et al., 2005a) report between 3% and 8% of participants having experienced side-effects from CAM treatment, mostly of a transient nature. This trend is supported by a Swedish study (Jacobsson et al., 2009) which notes the low reporting of CAM adverse drug reactions. This overall trend of low rates of side-effects is however not supported by all studies. Patients with gastric complaints in Turkey (Kav, 2009) and Germany (Joos et al., 2006) reported around 15% of side-effects from CAM use.

Some studies support citizens' perceived safety of CAM, or of a particular CAM therapy: UK and German prospective studies assessing the safety of acupuncture conclude that it is a relatively safe medical intervention (MacPherson et al., 2001; White et al., 2001; Witt et al., 2009). This conclusion is supported by a review of literature on clinical trials of acupuncture in the US, Canada, UK and Europe, based on meta-analyses and systematic reviews (Birch et al., 2004).

A correlation between the use of CAM and awareness or concerns about its safety and use has also been suggested. The authors of a questionnaire of primary care attendees in the UK argue that as patients experience CAM their awareness about safety and potential harm increases: 29% of users compared to 18% of non-users of CAM agreed with the statement 'CAM will do no harm' (Featherstone et al., 2003). These findings however contrast with

findings from Emslie et al.'s (2002) study, also in the UK. Comparing the use of CAM between 1993 and 1999 in similar study populations, these authors identify that although more people have used CAM in 1999, compared to 1993, fewer users seemed concerned about the safety of CAM use (25% in 1993 and 20% in 1999).

<b>CAM is natural, therefore safe/r, not involving risks and/or side-effects</b>	
<i>Denmark</i>	Jorgensen et al. 2005 laCour 2008
<i>Germany</i>	Bucker et al. 2008
<i>Italy</i>	Rossi et al. 2005 Zaffani et al. 2006
<i>Israel</i>	Brook et al. 2003 DeKeyser et al. 2001
<i>Portugal</i>	Nunes et al. 2006
<i>Switzerland</i>	Messerli-Rohrbach et al. 1999 Quattropani et al. 2003 Van der Weg et al. 2003
<i>Turkey</i>	Arguder et al. 2009 Kav et al. 2009
<i>UK</i>	Reid 2002 Sharpels et a. (2003) Shaw et al. 2008
Badger et al. 2007	
Furnham 2002	
Geramisisidis et al. 2008 Johnston et al. 200	
<b>CAM products are safer than biomedicine/pharmaceuticals</b>	
<i>Israel</i>	Giveon et al. 2004
<i>Italy</i>	Cuzzolin et al. 2009 Bacchini et al. 2008
<i>Turkey</i>	Aydin et al. 2008 Kav et al. 2009
<i>UK</i>	Holst et al. 2009 Lynch et al. 2007 Rhodes et al. 2008
<b>Some CAMs have a long history of use, thus safe/r</b>	
<i>UK</i>	Evans et al. 2007 Holst et al. 2009

Table 3: Citizens' perceptions and explanations of CAM safety

### ***Citizens' ways of ensuring the safety and quality of CAM provision***

Despite understanding CAM as 'natural', 'traditional' and/or safer than pharmaceutical preparations or biomedical interventions, and experiencing CAM treatments as generally 'safe', citizens do not automatically assume the safety and quality of CAM provision (Artus et al., 2007; Rhodes et al., 2008). Consequently, citizens draw on distinct strategies to assess and aim to ensure the safety and quality of their use of CAM. These include: CAM

endorsement and legitimacy conferred through biomedicine; registration with professional CAM bodies; CAM qualifications; and personal experience with CAM.

*CAM endorsement and legitimacy conferred through biomedicine*

A UK study with patients in primary care permits the identification of patterns of endorsement and legitimacy conferred to CAM via biomedical recommendation: 49% of respondents would use CAM only if referred to by a doctor; of those who had not used CAM in the past, 77% would use it if referred to by a doctor (Featherstone et al., 2003).

**Box 20: The importance of biomedical endorsement: views from qualitative UK studies**

The male cancer patients in Evans et al.'s (2007) study often expressed a preference for CAM to be provided through the National Health Service, since this was seen as a trusted source of care and brought with it a 'stamp of approval'.

Similar biomedical endorsement was also looked for by the cancer patients in Corner et al.'s (2009) study, and perceived to be particularly important to two different kinds of CAM users:

- People who had not used CAM prior to their cancer diagnosis
- Those who were CAM users for reasons unrelated to their cancer diagnosis but discontinued the use of CAM after their cancer diagnosis because of the lack of endorsement by biomedical professionals

Exploring patients' views at a NHS Homeopathic Hospital, Mercer et al. (2004) argue that patients were reassured about homeopathy and the treatment at the hospital by the fact that the providers are both medical doctors and qualified homoeopaths.

Citizens' wish of biomedical endorsement of CAM can also be seen in the general expectations citizens may have of their general practitioner about the referral to CAM providers. Ben-Ayre et al.'s (2009) Israeli participants for instance expect that their family physician would ensure the appropriate and safe referral to CAM providers. This wish for biomedical endorsement is however not confirmed in all studies: in 2000, fewer Israeli citizens consulted a CAM provider who held a biomedical diploma than in 1993 (56%; 72% respectively) (Shmueli & Shuval, 2004).

*Registration with professional CAM bodies*

Providers' registration with professional organisations is considered important by many citizens in the UK (Emslie et al. 2002; Evans 2007; Holst et al. 2009) and has increased in significance over time (Emslie et al. 2002). Emslie et al. (2002) report for the UK that while 52% of their participants thought registration with professional organisations was important in 1993, this figure has increased to 61% in 1999. For additional users perspectives, see Box 21.

**Box 21: The importance of professional registration: citizens' perspectives from the UK**

Given the diverse regulations of CAM providers in the UK citizens feel that it can be 'very difficult to know who is reputable and who is not reputable' and 'you actually got to do quite a bit of research to know who is safe to go to because anyone can stick some initials [to their name in the Yellow Pages]' (Holst et al. 2007: 227). Thus, being registered with a professional organisation confers some trust in CAM providers' safety as does working in well-known treatment centres (Evans et al. 2007).

*CAM qualifications*

Citizens in the UK are shown to refer to the qualifications held by CAM providers to ascertain providers' safety and potential quality of provision (Emslie et al. 2002; Evans 2007). Emslie et al. (2002) report that 40% of their study participants had enquired about the qualifications of the CAM provider prior to commencing treatment. These enquiries included: checking or seeing certificates in a clinic, or asking the CAM provider for details.

Not all citizens however may consider it necessary to vet the quality and safety of a CAM provider and their provision by checking qualifications, as their trust in the safety of services may rest in the legal provision that frame the practice of CAM. For instance, in Italy the practice of CAM as a means of treating diseases is legally reserved for physicians only. However, between 23%-36% of physicians in Tuscany and Parma had no certified training in the CAM therapy they practised (Cocconi et al., 2006; Giannelli et al., 2007). Specific training was reported by about 60% of Tuscan respondents practising acupuncture and homeopathy, and 28% of those practising manipulative therapies (Giannelli 2007). A similar situation is reported from Switzerland where 21% of all nurses practising CAM have received specific training (Siegenthaler & Adler, 2006). These findings support the opinions of key decision makers in German medical schools who associate the risks of CAM primarily with inadequate quality control of CAM provider training (72%) and the undifferentiated use of CAM and naturopathy by biomedical professionals (69%) (Brinkhaus et al., 2005).

*Citizens' personal experience with CAM*

Therapies were also seen as credible and legitimate if they were recommended by trusted individuals (for example Evans et al. 2007; Holst et al. 2009) (see Box 22 and Section 3.1).

**Box 22: Citizens' strategies to ensure the safety and quality of their CAM use**

Endorsement and legitimacy conferred via biomedicine  
(Evans et al. 2007, Corner et al. 2009, Featherstone et al. 2003, Ben-Ayre et al. 2009)

CAM provider registration with professional CAM bodies  
(Emslie et al. 2002, Evans et al. 2007, Holst et al. 2009)

Recognised CAM qualification  
(Emslie et al. 2002, Evans et al. 2007)

Personal experience with CAM

### 3.3.3 Citizens' needs concerning the quality of care in CAM

The above examination of citizens' perceptions and explanations concerning CAM safety and their strategies to ensure the quality and safety of CAM broadly reflects their needs regarding CAM quality and safety. Citizens' sources of evidence of CAM safety highlight that these differ from scientific notions of evidence and evidence-based healthcare practice and policy (Brinkhaus et al., 2005; Lewith & Chan, 2002b; van Haselen & Fisher, 1999; Williams & Mitchell, 2007; Wye et al., 2009). Some therefore argue that citizens' require biomedical professionals and policy makers to cede the power they wield by drawing on the rhetoric of 'scientific evidence' and to acknowledge the legitimacy of patients' sources of evidence (Wye et al., 2009).

As also noted, citizens particularly stress the importance of CAM providers' meaningful and transparent registration with professional CAM bodies. Furthermore, studies from Italy and Germany in particular highlight the importance of recognised CAM qualifications for all CAM providers, irrespective of other healthcare education and training, to ensure citizens' safety and the practice of CAM by appropriately qualified healthcare professionals.

### 3.3.4 Summary and conclusion

The literature that explores citizens' attitudes and needs concerning the quality of care in CAM highlights that citizens emphasise distinct aspects of CAM practice and draw on a range of explanations and strategies to evaluate the safety and quality of CAM provision. In their encounter with CAM providers, citizens particularly value the following:

- Empathetic communication in consultations with more time available than in biomedical encounters
- Involvement in their own care through e.g. decision-making about their treatment options, including the decision to terminate CAM treatment, and the provision of self-help strategies
- Whole person approach and person-centred healthcare
- Explanatory frameworks within which to explore health and illness, which are frequently congruent with citizens' own ideas about health and illness.

In addition, some studies also show that citizens are critical about CAM provider practices and terminate their treatments when they are not satisfied.

Citizens do not *a priori* assume the safety and quality of CAM provision. To evaluate the safety of CAM and/or CAM products, citizens emphasise three main considerations:

- CAM and CAM products are natural and therefore safe
- The long historical use of some CAM therapies demonstrates safety

- CAM and/or CAM products are safe/r when compared to biomedical treatment and/or pharmaceuticals

Only few studies, and mostly studies from the UK, have examined how citizens assess the safety and quality of CAM provision. Based on the limited knowledge available, the following general observations can be made:

- Citizens value biomedical endorsement of CAM and the legitimacy this confers
- Citizens consider transparent CAM registration with professional bodies to be important
- Citizens refer to CAM qualifications to assess the quality and safety of CAM provision

Citizens also draw on personal experience to evaluate CAM, CAM provision and/or providers, as noted in previous sections.

In addition, the importance of CAM qualifications for all those who practise CAM is also noted by some biomedical professionals.

In sum, although citizens' assessment of the safety of CAM may be based on limited scientific evidence and thus may differ from assessments of CAM safety by biomedical professionals, citizens are forming their own considered judgment about what is an acceptable level of risk concerning their use of CAM. In doing so, they are making meaningful decisions and establish priorities for their healthcare within their own frames of reference and value systems. In assessing the safety and quality of CAM provision, citizens indicate that they would like to be guided by biomedical professionals and stress the importance of transparency concerning CAM qualifications and professional registration.

On the basis of the literature reviewed, the following main gaps in knowledge about quality of care in CAM can be noted:

- How issues concerning the CAM provider-patient relationship play out for
  - different groups of citizens
  - in relation to a diversity of CAM modalities
  - in diverse settings (e.g. in private practice, integrated services)
  - and when offered by different CAM providers (e.g. non-biomedically qualified CAM providers; different groups of biomedical professionals with CAM training)
- How ethical dimensions of CAM practice are conceptualised and ethical responsibilities of CAM providers practised by diverse CAM providers and in diverse settings of CAM provision
- How different economic pressures and different social and cultural approaches affect the CAM provider-patient relationship

- Examination of the cost-effectiveness of CAM in terms of time and the provider-patient relationship vis-a-vis the clinical effectiveness of CAM
- How different groups of citizens evaluate the safety and quality of CAM provision (e.g. individual CAM therapies) in a diversity of settings and by different CAM providers
- The role of staff in pharmacies, chemists and health-food shops in supporting the safe use of over-the counter CAM products, particularly herbal medicines.

## 4 Conclusions and recommendations for future research

So far, this report has explored in detail available knowledge about citizens' attitudes and needs concerning CAM and has focused on presenting details about individual EU countries. In this section, these detailed findings are drawn together and presented as broad patterns. This is followed by sketching the recent proposal for a European framework programme for research entitled '*Horizon 2020*' as a possible basis for further research into CAM. We conclude with recommendations for future research relating to citizens' attitudes and needs concerning CAM and indications of how these will be taken forward in the wider context of CAMbrella.

### 4.1 Broad patterns of citizens' attitudes and needs concerning CAM in Europe

#### 4.1.1 Information about CAM

Citizens' attitudes and needs regarding information about CAM reveal a multi-dimensional decision-making environment in which both citizens' attitudes and their needs are embedded. Some distinct differences in citizens' attitudes to sources of information about CAM can be noted (see Table 4). In some countries, such as the UK, Turkey, Israel, Norway and Ireland, citizens' personal social networks constitute the main source of information about CAM. Though biomedical professionals as a source of information are relatively less important in these countries, some research indicates that citizens would like to receive information about CAM from biomedical professionals. By contrast, in countries such as Germany and Italy, biomedical professionals constitute an important information source about CAM, with social networks at times tending to be relatively less significant.

Shared across these differences is the importance of personal experience with CAM, which informs citizens' decisions about future CAM use and the recommendation of CAM through social networks and in professional contexts. In addition, citizens draw on print and broadcast media to inform themselves about CAM. At the time when the majority of articles on which this review is based was published, the internet appears to play a limited role as source of information about CAM; this may however have changed over recent years. Similarly, citizens appear to make limited use of CAM providers and their associations as information source.

This review of literature has identified a broad spectrum of disclosure rates of CAM use to biomedical professionals in different EU countries. This may point towards a correlation between the extent to which CAM is practised by biomedical professionals and citizens' disclosure of their interest in or use of CAM, and indicate that biomedical attitudes to CAM may support or limit the extent of discussion of CAM in biomedical encounters.

A link between the availability of information about CAM and citizens' non-use of CAM is noted in the majority of studies which examine citizens' reasons for not using CAM. This further highlights the need for the availability of accessible, reliable and trustworthy information about CAM to enable citizens to make informed choices about their healthcare.

<b>Countries</b> e.g. UK, Ireland, Israel, Norway, Turkey	<b>Countries</b> e.g. Germany, Italy
<b>Citizens' sources of information about CAM</b>	
1. Social networks 2. Biomedical professionals BUT: citizens would like information via biomedical professionals	1. Biomedical professionals 2. Social networks
3. Importance of personal experience 4. Print and broadcast media 5. Low importance of CAM providers as information source	
<b>Spectrum of disclosure of CAM use to biomedical professionals</b>	
From: Low disclosure of CAM use	To: High disclosure of CAM use (e.g. Germany and Switzerland)

Table 4: Citizens' attitudes to information about CAM

#### 4.1.2 Access to CAM

Despite the diversity of methodologies and approaches to data collection that the studies in this review have identified, citizens' positive attitudes to CAM, and citizens' demand of and support for increased and more diverse CAM provision is well established across a number of EU countries (see Table 5). At the same time, the majority of citizens would like biomedical professionals to be more supportive of and more knowledgeable about CAM, and thus also have a greater role in terms of referral to CAM and as information source.

Citizens' demand for increasing availability of CAM in public health services links with their needs concerning access to CAM, such as the barriers to CAM use they experience and/or perceive and their wish for a more active role of biomedical professionals in supporting their CAM use. The importance citizens (like biomedical and CAM professionals) attach to the research of CAM not only supports the availability of knowledge, but can also be seen as legitimising citizens' demands for CAM and for the diversity of CAM provision through increasing the recognition of CAM and/or particular CAM therapies. In turn, increasing recognition and legitimacy of CAM may meet citizens' needs by reducing barriers to CAM use, such as the financial cost of CAM when provided in the private healthcare sector.

Countries e.g. UK, Denmark, Israel,	Countries e.g. Germany, Switzerland,
<b>Support and need for</b>	
<ol style="list-style-type: none"> <li>1. Increased CAM provision</li> <li>2. Provision of CAM in public healthcare services</li> <li>3. Diversity of CAM provision and CAM providers</li> <li>4. Increasing research into CAM</li> </ol>	
<b>Barriers</b>	
Financial (and other) costs (e.g. out of pocket expenses)	Financial (and other) costs (e.g. limited reimbursement through health insurance)
<ol style="list-style-type: none"> <li>1. Biomedical professionals attitudes to CAM</li> <li>2. Limited provision in public healthcare services and provision of particular CAMs only, depending on available evidence of safety, quality and effectiveness</li> </ol>	

Table 5: Citizens' attitudes and needs concerning access to CAM

#### 4.1.3 Quality of care in CAM

Citizens' attitudes and needs concerning the quality of care in CAM highlight that citizens value distinct aspects of CAM practice, including the CAM provider-patient relationship and the collaborative premise of CAM with associated greater involvement in one's own care; a whole person approach frequently associated with the practice of CAM; and explanatory frameworks that are often congruent with citizens' own ideas about health and illness (see Table 6). Despite this, citizens are also critical of CAM practice and willing to terminate CAM treatment when it does not fulfill their needs and/or expectations.

Citizens are shown to not *a priori* assume the safety and quality of CAM provision. In assessing the safety and quality of CAM provision, citizens indicate that they would like to be guided by biomedical professionals, stress the importance of transparency concerning CAM qualifications and emphasise the need for increased and transparent regulation and registration of all CAM providers. Alongside, they also value personal experience with CAM. Thus, although citizens' assessment of the safety and quality of CAM may be based on limited scientific evidence and may differ from such assessments by biomedical professionals, citizens are forming their own considered judgment about what is an acceptable level of risk concerning their use of CAM. In doing so, they are making meaningful decisions and establish priorities for their healthcare within their own frames of reference and value systems.

Across many EU countries	
<b>Practice of CAM</b>	
1. Citizens value CAM provider-patient relationship 2. Citizens appreciate the values underpinning CAM practice (e.g. person-centred care, personal involvement in own care; whole person approach) 3. Critical of CAM practice (e.g. Israel, Denmark, Germany)	
<b>Safety and quality of CAM</b>	
Citizens' use of diverse strategies to ensure safety and quality of CAM provision - e.g. UK	Reliance on regulatory systems and biomedical endorsement of CAM provision (via biomedical provider) – e.g. Germany, Italy

Table 6: Citizens' attitudes to the quality of care in CAM

#### 4.1.4 Summary

Citizens' attitudes to CAM can be seen to be characterised by some differences, but also share many similarities. It can be tentatively suggested that there might be a correlation between citizens' attitudes to CAM and the extent to which CAM is practised by biomedical professionals. By contrast, a set of 'core needs' seem to characterise citizens' needs regarding CAM, and focus on:

- The availability of impartial, reliable and trustworthy information about CAM, in order to make informed decisions about use or non-use of CAM
- The widening of access to and diversity of choice of CAM provision and providers
- Clear regulatory and educational frameworks to help ensure the safety and quality of CAM provision

## 4.2 'Horizon 2020': EU developments in health research

The political framework for the future development of the EU is set out in the EU's growth strategy paper called 'Europe 2020'.<sup>15</sup> To respond to the economic crisis and to the strengthen the EU's global competitiveness in research, innovation and technology, a first proposal for a framework programme of research entitled 'Horizon 2020'<sup>16</sup> was published

<sup>15</sup> <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:2020:FIN:EN:PDF>

<sup>16</sup> [http://ec.europa.eu/research/horizon2020/pdf/proposals/proposal\\_for\\_a\\_council\\_decision\\_establishing\\_the\\_specific\\_programme\\_implementing\\_horizon\\_2020\\_-\\_the\\_framework\\_programme\\_for\\_research\\_and\\_innovation\\_\(2014-2020\).pdf#view=fit&pagemode=none](http://ec.europa.eu/research/horizon2020/pdf/proposals/proposal_for_a_council_decision_establishing_the_specific_programme_implementing_horizon_2020_-_the_framework_programme_for_research_and_innovation_(2014-2020).pdf#view=fit&pagemode=none)

by the European Commission in November 2011. This will be carried out between 2014 and 2020 and presumably funded with €89 billion.

To tackle major issues shared by citizens in Europe and elsewhere, ‘*Horizon 2020*’ will focus on peoples’ concerns about their livelihoods, safety and environment. It will address distinct priorities which correspond with those of ‘*Europe 2020*’ and the European Commission’s ‘*Innovation Union*’<sup>17</sup>. These priorities include: (1) ‘Excellent Science’ (2) ‘Industrial Leadership’ and (3) ‘Societal Challenges’.

As part of the priority ‘Societal challenges’, issues relating to ‘**Health, demographic change and wellbeing**’ are identified as some of the top challenges for future research (‘*Horizon 2020*’, p50-54), and for which a budget of about €8 billion is proposed. Specific objectives for research topics in this area are listed as orientation, such as:

*Understanding the determinants of health, improving health promotion and disease prevention*

A better understanding of the determinants of health is required in order to provide evidence for effective health promotion and disease prevention; this will also allow the development of comprehensive health and wellbeing indicators in the EU. Environmental, behavioural, and genetic factors, in their broadest senses will be studied.

*Developing cost-effective screening programmes and improving the assessment of disease susceptibility*

Identifying individuals and populations at high-risk of disease will allow personalised, stratified and collective strategies for disease prevention to be developed.

*Understanding disease*

There is a need for an improved understanding of health and disease, in people of all ages, so that new and better prevention measures, diagnosis and treatments can be developed.

*Active ageing, independent and assisted living*

Multidisciplinary advanced and applied research and innovation with behavioural, gerontological, digital and other sciences is needed for cost effective user-friendly solutions for active, independent and assisted daily living for the ageing population.

*Individual empowerment for self-management of health*

Empowering individuals to improve and manage their health throughout life will result in cost savings to healthcare systems by enabling the management of chronic disease outside institutions and improve health outcomes. Among others, this requires research into behavioural and social models, social attitudes and personalised services which promote a healthy lifestyle, wellbeing, self-care, improved citizen/healthcare professional interaction,

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<sup>17</sup> <http://ec.europa.eu/dgs/jrc/index.cfm?id=1370>

personalised programmes for disease and disability management, as well as support for knowledge infrastructures.

#### *Promoting integrated care*

Supporting the management of chronic disease outside institutions also depends on improved cooperation between the providers of health and social or informal care.

'*Horizon 2020*' also aims to support consumers to make informed choices, taking into account their own preferences, attitudes, needs, behaviour and lifestyles (p54-58). Therefore, and since European taxpayers have a right to know how their money is spent and given that innovation is vital to people's future, one major aim of '*Horizon 2020*' will be the dissemination of information, the communication of research activities and outcomes, and the promotion of Open Access.

In summary, it can be suggested that since '*Horizon 2020*' and CAM as a healthcare practice share several principles, '*Horizon 2020*' may constitute a potential funding source for future research in the field of CAM and related subjects. The shared principles, particularly in relation to the above focus on health, demographic change and wellbeing, include, for example: health promotion and disease prevention; understanding health and disease; active aging and independent living; individual empowerment for self-management of health; and the promotion of integrated care. Thus, the specific priorities of '*Horizon 2020*' represent a basis for further research in the field of CAM, including issues relating to citizens attitudes and needs concerning CAM in Europe.

### **4.3 Future research of citizens' attitudes and needs concerning CAM**

In the context of '*Horizon 2020*' and in light of the literature reviewed in this report, a number of recommendations for future research into citizens' attitudes and needs concerning CAM can be made.

In relation to the '*Horizon 2020*' objectives of understanding determinants of health and of studying behavioural factors of health, together with the commitment to fully integrate social science and humanities research into each of the '*Horizon 2020*' objectives (p20) pan-European studies in the field of CAM should aim:

- To address methodological issues in researching citizens' attitudes and needs concerning CAM in relation to information about CAM, access to CAM, and quality of care,
- To develop comparable and compatible research on citizens' attitudes and needs in relation to information about CAM, access to CAM, and quality of care,
  - In the complete range of EU countries,

- Through parallel studies in several EU countries.
- To develop innovative research approaches of investigating citizens' attitudes and needs in relation to information about CAM, access to CAM, and quality of care, including:
  - Approaches that acknowledge the importance and benefits of qualitative research for in-depth explorations of locally situated practice, such as 'mixed methods' studies,
  - Inter-disciplinary research that involves CAM providers and citizens as research partners.

Concerning the '*Horizon 2020*' topic of 'promoting integrated care' studies should be carried out that aim:

- To investigate the implications of citizens' diversity and the diversity of CAM with regard to citizens' attitudes and needs in relation to information about CAM, access to CAM, and quality of care, in terms of diversity of:
  - Citizens (e.g. gender, age, ethnicity, social class),
  - CAM practices and modalities,
  - CAM provision,
  - Locally situated CAM practices and terminologies.
- To investigate the access to CAM in Europe:
  - How different citizens (and groups of citizens) access CAM and individual CAM modalities, and what motivates some people not to use CAM,
  - How attitudes to CAM held by various groups of biomedical professionals shape and influence citizens' utilisation of CAM and/or particular CAM therapies,
  - How citizens' processes of accessing CAM are related to an understanding of a notion of 'cost' beyond financial implications,
  - The existing diversity of CAM provision, comprising the range of CAM therapies; the provision of CAM therapies within and outside of public health services; and by both biomedically trained CAM providers and providers trained exclusively in CAM,
  - Citizens' patterns of accessing CAM depending on a diversity of provision,
  - The cost-effectiveness of CAM provided in public healthcare systems,
  - The social implications of privately funded CAM treatments.
- To carry out studies on the quality of care in CAM:
  - How issues concerning the CAM provider-patient relationship play out for
    - different groups of citizens,
    - in relation to a range of CAM modalities,

- in diverse settings (e.g. in private practice, integrated services),
- and when offered by different CAM providers (e.g. non-biomedically qualified CAM providers; different groups of biomedical professionals with CAM training).
- How ethical dimensions of CAM practice are conceptualised and ethical responsibilities of CAM providers practised by diverse CAM providers and in diverse settings of CAM provision,
- How different economic pressures and different social and cultural approaches affect the CAM provider-patient relationship,
- Examine the cost-effectiveness of CAM in terms of time and the provider-patient relationship vis-a-vis the clinical effectiveness of CAM,
- How different groups of citizens evaluate the safety and quality of CAM provision (e.g. individual CAM therapies) in a diversity of settings and by different CAM providers,
- The role of staff in different commercial outlets selling CAM products in supporting the safe use of CAM products.

The right of European taxpayers to make informed consumer choices and be informed about research and its outcomes, together with the 'Horizon 2020' priority of 'individual empowerment for self-management of health' suggest the need for future research concerning citizens' need for information about CAM, including:

- What precisely citizens' information needs about CAM are (such as the content and type of information required, preferences for different media),
- How different groups of citizens (and in different EU countries) access and use information about CAM, individual CAM modalities and/or CAM products,
- The role of CAM providers as source of information,
- The role of staff in pharmacies, health-food shops and chemists in providing information about CAM, particularly about CAM products,
- How existing CAM research evidence can be disseminated more effectively,
- How disclosure of CAM use to biomedical professionals plays out for different groups of citizens and/or different biomedical professionals; in relation to different CAM modalities and/or products; and in a range of EU countries with different kinds of CAM provision and regulations.

#### **4.4 A roadmap for future CAM research: Linking with CAMbrella WP7**

The rich findings and recommendations resulting from the work of WP3, and which are presented in this report, will contribute – together with the findings and recommendations of other CAMbrella Work Packages – to the work of WP7. The task of WP7 is to consider the conclusions and recommendations of all CAMbrella Work Packages to then present

overall suggestions for a strategic agenda for future research topics in the field of CAM. In this way, CAMbrella will conclude its work with a roadmap for future CAM research in Europe that is based on an encompassing and coordinated approach.

## References

Full reference	Country	Quality of reporting (High, medium, low)	Information about CAM	Access to CAM	Quality of care in CAM
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<b>Unkelbach, R. and Abholz, H.H.</b> (2006), '[Differences between patients of conventional and anthroposophic family physicians]', <i>Forsch Komplementmed</i> , 13, 6, 349-55.	DE	M			X
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<b>Yilmaz, M.B., Yontar, O.C., Turgut, O.O., Yilmaz, A., Yalta, K., Gul, M. and Tandogan, I.</b> (2007), 'Herbals in cardiovascular practice: are physicians neglecting anything?', <i>Int J Cardiol</i> , 122, 1, 48-51.	TR	L	X		
<b>Zaffani, S., Cuzzolin, L. and Benoni, G.</b> (2006), 'Herbal products: behaviors and beliefs among Italian women', <i>Pharmacoepidemiology and Drug Safety</i> , 15, 5, 354-359.	IT	L	X		X
<b>Zanini, A., Quattrin, R., Goi, D., Frassinelli, B., Panariti, M., Carpanelli, I. and Brusaferrò, S.</b> (2008), 'Italian oncology nurses' knowledge of complementary and alternative therapies: national survey', <i>Journal of Advanced Nursing</i> , 62, 4, 451-456.	IT	M	X		
<b>Zuzak, T.J., Zuzak-Siegrist, I., Simoes-Wust, A.P., Rist, L. and Staubli, G.</b> (2009), 'Use of complementary and alternative medicine by patients presenting to a Paediatric Emergency Department', <i>Eur J Pediatr</i> , 168, 4, 431-7.	CH	M	X		X

## Appendices

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## Appendix 1: Search strategy

The following **databases** were used:

- Pubmed
- Web of Science
- CINHALL
- AMED
- PsycINFO and PsycARTICLES

The following **inclusion criteria** were adopted:

1. Design
  - a. Quantitative
  - b. Qualitative
  - c. Literature reviews
2. Participants
  - a. Citizens in the EU
  - b. In any EU 39 country
  - c. All ages
3. Languages
  - a. Any EU language

The following **exclusion criteria** were adopted:

1. No abstract
2. Abstract not in English
3. Presentation as abstract only
4. Outside EU (or Turkey, or Israel)
5. Editorials, letters, opinion pieces
6. Duplicates
7. Studies reporting on clinical treatment or treatment evaluation (e.g. RCTs, outcome studies)
8. Studies reporting on medicinal use of a single herb, herbal compound, homeopathic remedy, aromatherapy oil, natural substance (e.g. isoflavenoids from soya), or treatment technique (e.g. chiropractic) for particular conditions and/or by particular groups (e.g. nettle used by cancer patients in Turkey)

**Limits:** 01 January 1989 to 31 December 2009

## Appendix 2: Search terms

### 2.1: Search terms - general

Two related main searches were carried out, referred to as Search 1 and Search 2. The over-arching search terms for these searches are as follows:

- CAM:
  - For searches in Pubmed, the MeSH term 'complementary therapies' was used (see below, MeSH term exploded).
  - For the remaining databases, the following search string for 'CAM' was used: Complementary medicine\* OR alternative medicine\* OR complementary therap\* OR alternative therap\* OR integrative medicine\* OR integrative therap\*.
- Europe: To identify abstracts focusing on citizens' attitudes and needs in EU countries
  - For Pubmed searches the search string 'Europe (MeSH) OR Turkey OR Israel' was used
  - Searches in Web of Science were refined using additional data base search facilities.
  - Selections about abstracts from all other databases were made after reading title and abstract, and if needed the full articles.
- Citizen, attitude, need (see below)

### 2.2: Pubmed MeSH term 'complementary therapies'

When using the term 'Complementary Therapies' in the Pubmed database, all the following 'entry terms', 'MeSH categories' and 'therapeutics' are included. This allows for an exceptionally wide search.

Entry Terms:

Therapies, Complementary  
Therapy, Complementary  
Complementary Medicine  
Medicine, Complementary  
Alternative Medicine  
Medicine, Alternative  
Alternative Therapies  
Therapies, Alternative

Therapy, Alternative

All MeSH Categories

Analytical, Diagnostic and Therapeutic Techniques and Equipment Category

Therapeutics

Complementary Therapies

Acupuncture Therapy

Acupuncture Analgesia

Acupuncture, Ear

Electroacupuncture

Meridians

Acupuncture Points

Moxibustion

Anthroposophy

Auriculotherapy

Acupuncture, Ear

Holistic Health

Homeopathy

Medicine, Traditional

Medicine, African Traditional

Medicine, Arabic

Medicine, Unani

Medicine, Ayurvedic

Medicine, East Asian Traditional

Medicine, Chinese Traditional

Qi

Yin-Yang

Medicine, Kampo

Medicine, Korean Traditional

Medicine, Tibetan TraditionalMedicine

Medicine, Mongolian Traditional

Shamanism

Mind-Body Therapies

Aromatherapy

Biofeedback, Psychology

Breathing Exercises

Hypnosis

Autogenic Training

Suggestion

Autosuggestion

Imagery (Psychotherapy)

Laughter Therapy

Meditation

Mental Healing

Mind-Body Relations (Metaphysics)

- Psychodrama
  - Role Playing
- Psychophysiology
- Relaxation Therapy
- Tai Ji
- Therapeutic Touch
- Yoga
- Musculoskeletal Manipulations
  - Acupressure
  - Kinesiology, Applied
  - Manipulation, Chiropractic
  - Manipulation, Osteopathic
  - Massage
- Naturopathy
- Organotherapy
  - Tissue Therapy
- Phytotherapy
  - Aromatherapy
  - Eclecticism, Historical
- Reflexotherapy
- Rejuvenation
- Sensory Art Therapies
  - Acoustic Stimulation
  - Aromatherapy
  - Art Therapy
  - Color Therapy
  - Dance Therapy
  - Music Therapy
  - Play Therapy
- Speleotherapy
- Spiritual Therapies
  - Faith Healing
  - Homeopathy
  - Magic
  - Medicine, African Traditional
  - Meditation
  - Mental Healing
  - Occultism
  - Radiesthesia
  - Shamanism
  - Therapeutic Touch
  - Witchcraft
  - Yoga

### 2.3: Search terms - Search 1

Search 1 used three key search terms – citizen, attitude and need - and a number of synonyms. See Table 1 below.

<b>Citizen</b>	<b>Need</b>	<b>Attitude</b>
Public Population Consumer Inhabitant Resident	Demand Reason Expectation Motivation Barrier Requirement	Belief Awareness Acceptance Value Philosophy World view Choice Knowledge Inclination Perception Approach Outlook Position Opinion Point of view Openness
Pubmed: Humans (MeSH)	Pubmed: As above	Pubmed: Attitude to Health (MeSH)

Table 1: Search 1 - key terms and synonyms

### 2.4: Search terms - Search 2

Information  
Quality of care  
Decision-making  
Disclosure  
Safety  
Access  
Cost  
Evidence  
Effectiveness  
Regulation

Search 2: sources of search terms

1. Recurring key terms in Search 1
  - a. Information
  - b. Quality of care
  - c. Decision-making
  - d. Disclosure
  - e. Safety

- f. Access
  - g. Cost
  - h. Evidence
2. Key conclusions and priorities identified by stakeholders (see above, section 3.1 Stakeholder workshop)
- a. Independent and accessible information
  - b. Quality of care
  - c. Equal access to services
3. CAMbrella proposal
- a. Information
  - b. Quality
  - c. Safety
  - d. Regulation
  - e. Effectiveness

### Appendix 3: Search results

Search 1 and Search 2 were carried out separately. All identified titles and abstracts were read and selected according to the above in/exclusion criteria.

Search 1 identified a total of 2.796 abstracts of which 323 met in/exclusion criteria (see Table 2 below).

Search 2 identified 3.698 abstracts of which 194 met in/exclusion criteria (see Table 3 below).

	<b>Search 1</b>	
	Hits	Abstracts meeting in/exclusion criteria
<b>Pubmed</b>	1.684	267
<b>Web of Science</b>	1.091 445 (EU)	43
<b>CINHAL and AMED</b>	250	13
<b>PsycINFO, including PsycARTICLES</b>	417	0
<b>Total</b>	<b>2.796</b>	<b>323</b>

Table 2: Summary of search results for Search 1

	<b>Search 2</b>	
	Hits	Abstracts meeting in/exclusion criteria
<b>Pubmed</b>	1.028	98
<b>Web of Science</b>	509	38
<b>CINHAL and AMED</b>	1.290	24
<b>PsycINFO, including PsycARTICLES</b>	871	34
<b>Total</b>	<b>3.698</b>	<b>194</b>

Table 3: Summary of search results for Search 2

## Appendix 4: Quantitative studies: Assessing the quality of reporting and evaluating the relevance for WP3

**4.1: Categories for assessing the quality of reporting of quantitative studies**, based on: Elm E, Altman DG, et al (2007), The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: Guidelines for Reporting Observational Studies, *Annals of Internal Medicine* 147, 8: 573-577

Methods					
Addresses specific question and objectives	States study design and further details	Describes setting (e.g. location, dates, recruitment period)	Gives eligibility criteria,	Describes variables (e.g statistical methods; sampling)	Description of how study size was arrived at

Results					CAM	
Response rate reported	Description of study participants	Main results clearly described	Other results described	limitations discussed	CAM definition reported Or description of individual therapy)	CAM modalities listed (as a means of 'definition')

Table 4: Categories for assessing the quality of reporting of quantitative studies

### 4.2: Assessing the quality of reporting

Q/A Category	Q/A Score	Number of articles
High (33 articles)	13	0
	12	8
	11	25
Medium (80 articles)	10	33
	9	24
	8	23
Low (37 articles)	7	19
	6	8
	5	10

Table 5: Results of the assessment of the quality of reporting

**4.3: Evaluating the relevance for WP3**

Score for relevance	Number of articles
3	33
2	71
1	44
0	2

Table 6: Results of the evaluation of the relevance for WP3

**4.4: Results of quality of reporting and relevance for WP3**

Q/A Category	Score for relevance	Number of articles
High (33 articles)	3	4
	2	21
	1	8
	0	0
Medium (80 articles)	3	21
	2	32
	1	23
	0	4
Low (37 articles)	3	9
	2	13
	1	15
	0	0

Table 7: Results of quality of reporting and assessment of relevance for WP3

## Appendix 5: Qualitative studies: Assessing the quality of reporting and evaluating the relevance for WP3

### 5.1: Categories for assessing the quality of reporting of qualitative studies, based on:

Malterud K (2001), Qualitative Research: Standards, Challenges and Guidelines, *Lancet* 358: 483-488

Methods				
Addresses specific aims and/or research questions	Research design are qualitative methods suitable; chosen qualitative methods suitable	Strategy for data collection stated; characteristics of sample, site, context etc are presented	Theoretical framework is presented; Role given for analysis	Data organisation and analysis are described; any particular principles mentioned

Findings			CAM	
Findings are relevant re research question; findings are clearly described	Additional findings reported	Short-comings are discussed; reflexivity; consequences of findings noted	CAM definition reported (or description of individual therapy)	CAM modalities listed (as a means of 'definition')

Table 8: Categories for assessing the quality of reporting of qualitative studies

### 5.2: Assessing the quality of reporting

Q/A Category	Q/A Score	Number of articles
High (10 articles)	13	3
	12	2
	11	5
Medium (16 articles)	10	4
	9	6
	8	6
Low (10 articles)	7	1
	6	6
	5	3

Table 9: Results of the assessment of the quality of reporting

### 5.3: Evaluating the relevance for WP3

Score for relevance	Number of articles
3	3
2	20
1	11
0	2

Table 10: Results of the evaluation of the relevance for WP3

**5.4: Results of quality of reporting and relevance for WP3**

<b>Q/A Category</b>	<b>Score for relevance</b>	<b>Number of articles</b>
High (10 articles)	3	1
	2	7
	1	2
	0	0
Medium (16 articles)	3	0
	2	10
	1	5
	0	1
Low (10 articles)	3	2
	2	3
	1	4
	0	1

Table 11: Results of quality of reporting and assessment of relevance for WP3