

Building a Sustainable Complementary and Alternative Medicine Research Network in Europe

Bettina Reiter^a Franziska Baumhöfener^b Meike Dlaboha^b Jesper Odde Madsen^{c,d}
Stephanie Regenfelder^e Wolfgang Weidenhammer^e

^a Vienna International Academy for Integrative Medicine, Vienna, Austria

^b Bavarian Research Alliance GmbH, Munich, Germany

^c University of Southern Denmark, Odense,

^d RESCOMM Communication Consultancy, Copenhagen, Denmark

^e Competence Centre for Complementary Medicine and Naturopathy, Klinikum rechts der Isar, Technical University, Munich, Germany

Keywords

CAM research · FP7 · Science communication and dissemination · Networking · Stakeholder

Summary

Background: Since CAMbrella is a networking project funded by the European Commission explicitly to build and sustain a complementary and alternative medicine (CAM) research network in Europe, communication and dissemination play a large role and form a work package of their own. The present article gives an outline of the communication and dissemination work in the CAMbrella consortium. The intensive building of sound internal communication is an essential part in establishing a functioning structure for collaboration in a diverse group of 16 partner institutions from 12 countries, as exists in the CAMbrella project. **Methods:** The means and tools for dissemination of results to the scientific community and the European public at large, as well as to the European policy makers, are presented. The development of the corporate design and a dissemination strategy are described in detail. In addition, some basic information regarding previous CAM research efforts, which might be interesting for future consortium building in the field of CAM research, is given. **Results:** Internal communication within a heterogeneous research group, the maintenance of a work-oriented style of communication and a consensus-oriented effort in establishing dissemination tools and products will be essential for any future consortium in the CAM field. **Conclusion:** The outlook shows the necessity for active political encouragement of CAM research and the desideratum of a Pan-European institution analogous to the NIH (National Institutes of Health) in the USA.

Introduction

CAMBrella is the acronym of an EU-funded project in the Seventh Framework Programme (FP7) of the EU, running between January 2010 and December 2012. The outline, design and the goals of CAMbrella have been described in detail in a previous article recently published in this journal [1]. The project's funding category is 'coordination and support action', i.e., support for activities aimed at coordinating or supporting research activities and policies (networking, exchanges, trans-national access to research infrastructures, studies, conferences, etc.) [2, 3].

An explicit task is the establishment and sustained maintenance of a European research network in complementary and alternative medicine (CAM) [4]. Therefore, CAMbrella has a strong focus on communication and dissemination of its processes and results. This focus in itself has to reflect the different needs that derive from different target groups and informational interests. The project has to ensure the networking process of the consortium internally, as well as the dissemination of the results to the scientific community and to various stakeholders.

The active communication of the scientific results to the wider public is a fundamental task of a project considered as a 'coordination and support' action. This relates to the level of the political decision makers (national and European) as well as to the European public at large. Work Package 8 (WP8) – 'dissemination and communication' has to ensure these claims. The fact that CAMbrella has its own working group on 'soft matters' like communication and dissemination reflects the need to establish a sound informational policy in CAM. The EU Commission (EC) recently underlined the importance of actively communicating scientific results to the

broad public by funding several projects within FP7 specifically dedicated to science communication issues, e.g., ‘CommHERE – Communicating European Health Research’ started in October 2011 [5], or ‘CommNET – Communicating the Bioeconomy’ in January 2012 [6]. The overall aim of these projects is to improve communication on the outcome of EU-funded projects in a research area to the media, the general public and other target groups, including the EC throughout Europe. The EU project on Traditional Chinese Medicine [7] is another example for an undertaking with distinct emphasis on networking, and brought together 29 beneficiary and 81 non-beneficiary collaborating partner organisations.

Identification of Target Audiences for Dissemination

Starting the CAMbrella project, a leading task was to actively search and look out for people in Europe involved in CAM research (and education) who at that point were not yet known to us. Consequently, we extended the fundamentals of a coherent network of CAM related organisations in Europe, using personal contacts in the existing network, asking the Advisory Board (which represents different groups of stakeholders such as consumers, practitioners, providers, and manufacturers of CAM medicinal products) to name relevant contacts in European countries, especially in Eastern and Southern Europe, and via our website.

51 institutions have registered via the website as potential stakeholders with an interest in CAM. They come from 16 European countries and India, Australia and Canada; they mostly represent health professional organisations or private and academic centres. They all will receive the final report and be asked whether they want to be listed in a research networking database.

Results from the Stakeholder Survey/Workshop

To discover more about the needs and wishes in terms of information and decision making, we tried to actively involve European stakeholders for health topics, but not directly related to CAM, in a dialogue.

A web-based survey was conducted and a workshop held in Brussels in April 2012. We invited approximately 40 European stakeholders in the health field to this workshop, the topic of which were: The informational needs of the European public about CAM – are they met by the existing channels, what else is needed? – Do the stakeholders feel CAM a relevant field in health care provision, and if so, do they feel that they know enough about it to feel safe in their recommendations and attitude towards CAM?

The response rate of the survey was 50% and based on the data of 20 organisations. The main findings of the survey were the following:

- 70% found the CAM issue of some relevance, important or very important for their organisation.
- 80% found the European citizens’ access to reliable information about CAM poor or very poor.
- 95% found it important or very important to meet the EU citizens’ need for more information on CAM in the future.
- 54% found the level of CAM information provided by EU health authorities poor or very poor.
- 60% of the organisations found their own access to information regarding the CAM situation in the European countries difficult or very difficult.

The most important informational needs regarding CAM in Europe concern:

- evaluation of treatments (77%)
- guidelines for CAM users (46%)
- access to research data (46%)

The workshop assembled a group of 13 people from different health backgrounds in a lively discussion about information accessibility, about providers and treatment methods, quality standards in education and information alike, and observable shifts in the public opinion as well as in the positions of policy makers. This provided useful insights for the dissemination strategy, with the attendants’ viewpoints markedly differing from what we had expected before the workshop. Attendants, for example, pointed out the strong interest in CAM for some European Parliament Members (MEP) compared to other health-related fields.

The Dissemination Strategy

The WP8 Programme included the development of a strategy of dissemination. This implies a twofold process: (i) the dissemination of results to the public, and (ii) internal communication in the group and development of a coherent message for the whole project. In the end (i) will enter (ii).

Dissemination of Results to the Public

The first step was the development of a corporate design (CD), including a project logo, poster, leaflet, brochure, website and newsletter, as well as letterheads to be used in correspondence by the consortium partners. This task was accomplished in spring 2010 – with the website (www.cam-brella.eu) being online since 1 April 2010 and the logo at the disposal of the partners via the web-based working platform that hosts all the projects documents (www.projectplace.com).

The website gives the general information about the participants, the goals, the distribution of work and all the contact details. There is also an invitation to subscribe to the quarterly newsletter and/or to the registration as a CAM stakeholder in Europe, thus trying to actively involve CAM-related research centres and other interested parties in the communicative process.

The quarterly newsletter is sent to around 800 recipients, collected either via self-registration on the website or using the existing networks of the participants. The newsletter combines information about the participating countries and their respective CAM situations, with portraits of relevant stakeholders in CAM and information about the project itself. By the end of the project, 12 newsletters will have been distributed.

In 2011, a Facebook profile (www.facebook.com/CAMBrella.eu) was set up to enable and enhance the communication with the wider public interested in CAM, and to learn more about the use of social media in a mixed context of research-related, but also a general informative setting; in March 2012 and with an eye on organising the final conference (29 November 2012), we added a CAMbrella Twitter account (<https://twitter.com/#!/CAMbrellaEU>), thus completing the social media presence of the project.

While the web-based tools of website and social media are directed at the general public, and may randomly hit someone actively involved in CAM research not already involved in the wider network, the dissemination to the political decision makers' level has to use and implement different tools. Therefore, WP8 will produce a 'Policy Brief' [8], i.e., a condensed brochure on the findings of all the WPs to inform the EC and the European Parliament. Other examples of dissemination tools tailored for different target groups are press releases aiming at the public at large and this special issue of *FORSCHENDE KOMPLEMENTÄRMEDIZIN/RESEARCH IN COMPLEMENTARY MEDICINE* aiming at the scientific community.

The scientific dissemination has also taken place at scientific conferences like those organised by the 'International Society for Complementary Medicine Research' (ISCMR) and the 'European Congress for Integrative Medicine' (ECIM), and via scientific publications like the papers assembled in this special issue of *FORSCHENDE KOMPLEMENTÄRMEDIZIN/RESEARCH IN COMPLEMENTARY MEDICINE*.

Internal Communication and Development of a Coherent Project Message

From the beginning, the whole consortium has been actively involved in the dissemination activities such as the CD development and the assessment of the quality of communication. As an internal steering tool for the latter, we conducted an online survey in spring 2011 amongst the consortium members asking them about their impressions on the quality of communication and their proposals for improvement, if needed. Results show that the communication process is fairly well rated, but there is still room for some improvement. This survey will be repeated in summer 2012.

Another feature of this active involvement was the process of finding a single project slogan to be the 'marketing tool' of CAMbrella. This slogan will be based on the reports of the different WPs (deliverables). WP leaders were asked to sum

up their findings in 'key messages' that formed the material for WP8 to mould the project slogan.

The overall slogan plays an important role in the non-scientific dissemination, but it will also help scientists to relate to the CAMbrella findings. The process is currently not yet finalised and the slogan will be presented during the final conference in November 2012 and published in all CAMbrella dissemination pathways.

CAM Networking within the EU so far

From 1993 to 1998 the EC set up the 'COST B4' project on unconventional medicine in Europe. In expert meetings over a period of 7 years, participants from 13 European countries tried to sort out questions about therapeutic significance, cost-benefit ratios and cultural and social importance of unconventional medicine. The project resulted in complex recommendations for future work in the CAM field, but these were never taken up in a consecutive project. Networking stayed personal and did not reach a structured level.

The FP5 funded a CAM project, the 'Concerted Action for Complementary and Alternative Medicine Assessment in the Cancer Field' (CAM-Cancer); CAM-Cancer aimed at providing evidence-based information on CAM treatments for cancer and assembled systematic reviews on various topics in this field. It is now hosted by the National Information Centre for Complementary and Alternative Medicine (NIFAB) at the University of Tromsø, Norway.

Even before the start of CAMbrella, there was a fairly well established informal network of CAM researchers with workshops and meetings of people from the European CAM community taking place since 2004 with the explicit goal of establishing a European consortium for EU funds to come into the CAM field. These informal meetings entered 'EURICAM', an interest group to explicitly get a European-funded CAM project going.

Most of the consortium members of CAMbrella were already involved in the EURICAM network and played an important role in achieving a consensus among a heterogeneous group of researchers about general research ideas. International ad-hoc meetings alongside of scientific conferences were used to gain support for this preparatory work. The development came along with tremendous efforts made by numerous CAM stakeholder groups organised on national and European levels.

The bridge-building function of the national contact points was also implicated. This networking process passed off in an increasingly more coordinated manner and gained momentum, when, in 2008, the WP for 2009 on the specific programme 'Cooperation', theme health was published by the EC, which incorporated a topic on CAM from which in the end CAMbrella evolved.

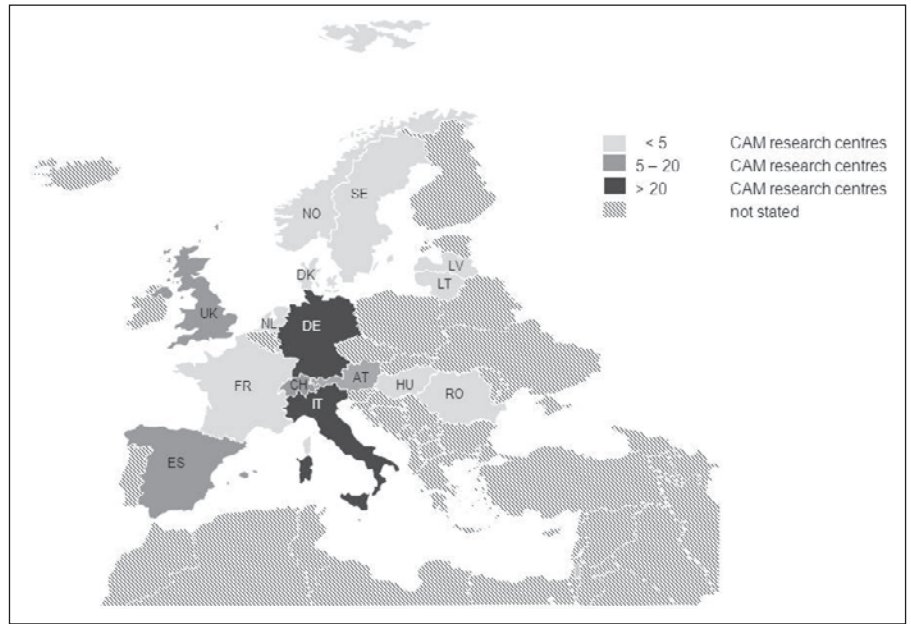


Fig. 1. Distribution of CAM research centres over Europe.

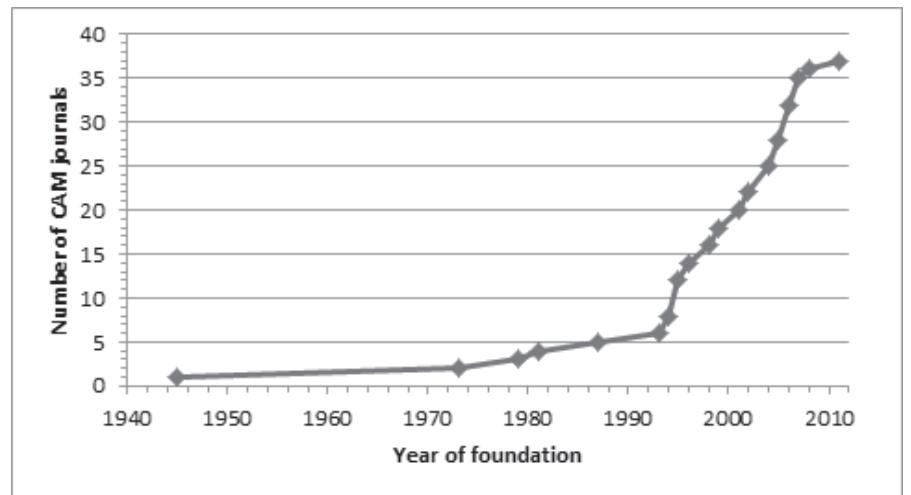


Fig. 2. Development of the number of international journals on CAM over the last 7 decades.

Experience with Pan-European Cooperation

Due to the prior experience of good cooperation and collegial atmosphere at the informal EURICAM meetings, the ground for a fruitful collaboration was already well prepared when the project started in 2010 with a kick-off event in Munich. Most of the people knew each other and the integration of the new partners were easily managed. The cooperation of the 16 partners from 12 countries was thus quickly and thoroughly established, helped by the fact that the WP leaders had very good co-workers in their teams to manage the daily work and the day-to-day-communication matters.

The same characteristic of friendly cooperation applies to the Advisory Board, whose members took a very active interest in the on-going work of the project and involved themselves in debates about the general lines of the project. They

were also very helpful in giving practical advice and infra-structural support, if needed.

Furthermore, the CAMbrella consortium built up contacts and started cooperation with other organisations in the field, e.g., PedCAM (Pediatric Complementary and Alternative Medicine Research and Education Network; <http://www.pedcam.ca/>), the EU Pediatric CAM initiative, the CAM-Doc Alliance (comprising ECH, ECPM, ICMART and IVAA; <http://www.camdoc.eu/>), the EURO-CAM group (alliance of European umbrella organisations of patients, physicians and practitioners in the field of CAM) or special MEP interest groups (CAM interest group or MEPs against cancer).

CAMBrella has maintained close relationships with the International Society on Complementary Medicine Research (ISCMR; www.iscmr.org), which established a special interest group, the European Chapter, in 2008. This organisation con-

Table 1. International journals on CAM

Name	ISSN	Scope	Impact factor (2010) ^a	Issues/year	Year of first issue ^b
Acupuncture & Electro-Therapeutics Research	0360-1293 (print) 2167-9010 (online)	basic and clinical research in acupuncture, electro-therapeutics, and related fields	0.250 (2009)	4	1998
African Journal of Traditional, Complementary and Alternative Medicines	0189-6016	applied medicinal plants, traditional medicines, complementary alternative medicines, etc.	0.457	3	2004
Alternative Medicine Review	1089-5159	alternative and complementary therapies	3.571	4	1996
Alternative Therapies in Health and Medicine	1078-6791	provide health care providers with continuing education to promote health, prevent illness, and treat disease	not stated	6	1995
BMC Complementary and Alternative Medicine	1472-6882	interventions and resources that complement or replace conventional therapies	2.200	12 ^c	2001
Chinese Journal of Integrative Medicine	1672-0415 (print) 1993-0402 (online)	integrative medicine as well as complementary and alternative medicine	0.578	12	1995
Chinese Medicine	1749-8546	all aspects of Chinese medicine	1.240 (unofficial impact factor)	12 ^c	2006
Chiropractic & Manual Therapies	2045-709X	evidence-based information that is clinically relevant to chiropractors, manual therapists and related health care professionals	not stated	12 ^c	2005
Complementary Therapies in Clinical Practice	1744-3881	effective and professional integration of complementary therapies within clinical practice	not stated	4	1995
Complementary Therapies in Medicine	0965-2299	objective and critical information on complementary therapies	1.484 (5-year impact factor: 1.990)	6	1993
European Journal of Integrative Medicine	1876-3820	strengthen the understanding and cooperation between conventional medicine and evidence-based complementary and alternative medicine	1.200	4	2008
Evidence-Based Complementary and Alternative Medicine	1741-427X (print) 1741-4288 (online)	complementary and alternative medicine modalities, particularly traditional Asian healing systems	2.964	4	2004
Explore: The Journal of Science and Healing	1550-8307	evidence-based healing practices from a wide variety of sources, including conventional, alternative, and cross-cultural medicine	0.795 (5-year impact factor: 1.055)	6	2005
Fitoterapia	0367-326X	medicinal plants and to bioactive natural products of plant origin	1.899 (5-year impact factor: 1.884)	8	1999
Focus on Alternative and Complementary Therapies	2042-7166	present the evidence on complementary and alternative medicine (CAM) in an analytical and impartial manner	not stated	4	1996

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Table 1. Continued

Name	ISSN	Scope	Impact factor (2010) ^a	Issues/year	Year of first issue ^b
Forschende Komplementärmedizin/ Research in Complementary Medicine	1661-4119 (print) 1661-4127 (online)	traditional and complementary/alternative medicine (CAM) on a sound scientific basis, promoting their mutual integration	1.059	6	1994
Homeopathy (formerly known as British Homeopathic Journal)	1475-4916	improving the understanding and clinical practice of homeopathy	1.000	4	1945
Integrative Cancer Therapies	1534-7354 (print) 1552-695X (online)	scientific understanding of alternative medicine and traditional medicine therapies, and their responsible integration with conventional health care	1.716	4	2002
Journal of Complementary and Integrative Medicine	1553-3840	evidence concerning the efficacy and safety of complementary and alternative medical (CAM) whole systems, practices, interventions and natural health products, including herbal medicines	not stated	1	2004
Journal of Ethnobiology and Ethnomedicine	1746-4269	promote the exchange of original knowledge and research in any area of ethnobiology and ethnomedicine	1.280 (unofficial impact factor)	12 ^c	2005
Journal of Ethnopharmacology	0378-8741	exchange of information and understandings about people's use of plants, fungi, animals, microorganisms and minerals and their biological and pharmacological effects based on the principles established through international conventions	2.466 (5-year impact factor: 3.216)	18	1979
Journal of Experimental and Integrative Medicine	1309-4572 (print) 2146-3298 (online)	entire field of biomedical sciences, particularly concentrated on the background of physiological and pathophysiological mechanisms from molecules to organ systems	not stated	4	2011
Journal of Manipulative and Physiological Therapeutics	0161-4754	advancement of chiropractic health care	1.418 (5-year impact factor: 1.458)	9	1999
Journal of Medicinal Food	1096-620X (print) 1557-7600 (online)	chemistry and biochemistry of the bioactive constituents of food and substantiates their efficacy, safety, and potential uses	1.461	12	1998
Journal of Medicinal Plants Research	1996-0875	medicinal plants research, ethnopharmacology, phytomedicine etc.	0.879	12 ^c	2007
Journal of Natural Medicines	1340-3443 (print) 1861-0293 (online)	naturally occurring medicines and their related foods and cosmetics	1.469	4	2006
Journal of Traditional Chinese Medicine	0255-2922	clinical and theoretical research in this branch of medicine	not stated	4	1981
Medical Acupuncture	1933-6586 (print) 1933-6594 (online)	evidence-based clinical papers, case reports, and research findings that integrate concepts from traditional and modern forms of acupuncture with conventional medical training	not stated	4	2007
Neural Regeneration Research	1673-5374	neural stem cells, neuroengineering, neurodegeneration and traditional Chinese medicine and acupuncture intervention	not stated	12	2006
Phytomedicine	0944-7113	phytopharmacology, phytotherapy and phytotoxicology	2.662	14	1994
Phytotherapy Research	0951-418X (print) 1099-1573 (online)	medicinal plant research	1.878	12	1987
Planta Medica	0032-0943	medicinal plants and natural products	2.040	18	2006

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Table 1. Continued

Name	ISSN	Scope	Impact factor (2010) ^a	Issues/year	Year of first issue ^b
Research Journal of Medicinal Plant	1819-3455 (print) 2151-7924 (online)	botany, biochemistry, phytochemistry, ethnopharmacology, phytomedicine, phytotherapy, ethno-medicine and pharmacognosy	not stated	6	2007
The American Journal of Chinese Medicine	0192-415X (print) 1793-6853 (online)	traditional or ethnomedicine of all cultures	1.383	6	1973
The Journal of Alternative and Complementary Medicine	1075-5535 (print) 1557-7708 (online)	to evaluate and integrate complementary and alternative medicine (CAM) into mainstream practice	1.498	12	1995
The Journal of Complementary Medicine	1446-8263	authoritative, practical and relevant information on complementary medicine to its readers' daily practices or businesses of maximising patient and customer well-being	not stated	6	2002
The Journal of Dietary Supplements (formerly known as Journal of Herbal Pharmacotherapy)	1939-0211 (print) 1939-022X (online)	important issues that meet a broad range of interests from researchers, regulators, marketers, educators and healthcare professionals	not stated	4	2001

^aPublished by Thomson Reuters (ISI) in 2011 if not stated otherwise.

^bAccording to information stated on the journal's website.

^cNo printed issues (open access).

stitutes a platform for researchers involved in complementary medicine, and promotes exchange and cooperation within Europe [9]. The CAMbrella network will stay in close contact with the European Chapter, thus enabling the maintenance and further sustainable development of the European network.

To facilitate the search for potential partners regarding future CAM research projects, we have generated a list containing the institutions of all our partners in the consortium and information on further institutions named by those partners and the advisory board members. This list will be stored on the project's website (www.cambrella.eu) and is planned to expand continuously. Consequently, this list is not intended to be exhaustive. To get first insights into the distribution of those centres that have been listed up to now see figure 1.

Increasing Research on CAM

There is not only a demand for more research on CAM but also an increased output by researchers working on CAM topics. This is evident by looking at the increasing number of international journals focusing on CAM over the last decades.

We looked at 37 international journals on CAM selected using the publications of Cong and Chen [10] and Fu et al. [11] as a basis, and established our own list by leaving out some of the journals that seemed too specific for us and adding some others that were known to us (table 1).

Figure 2 shows the development of the number of international journals on CAM over the last 7 decades. This graph results from data (year of foundation) that we found by web research. A strong increase in the number of journals since the mid 1990s can be seen.

It may be hypothesised that the increase during the late 1990s accompanied the growing claims for evidence-based medicine and the differentiation into various sub-topics (e.g., into pharmaceutical and basic research, especially in Asia). Recently, a shift can be observed that separates the 'traditional' CAM journals from the 'integrative medicine' journals that have established themselves at the borderline of conventional medicine.

Conclusions and Outlook

Europe lacks proper funding for CAM research. In comparison to the US where funding is provided by the National Center for Complementary and Alternative Medicine (NCCAM) at the National Institutes of Health (NIH), there is nothing similar in the European context.

An outcome of the WP8 stakeholder workshop in Brussels was the strong and joint opinion of participants that such an institution, similar to the NIH in the US, was urgently needed

in the Europe, i.e., a joint research and quality standards assessment body that is independent from regional and national influences and from industry – and other stakeholder interests.

A well-funded ‘European NIH’ would be the agent to get CAM research going on a broader scale and with the inclusion of the currently missing countries. A second drawback for CAM research is the diversity of CAM providers and educations. In most countries there are no academic centres for CAM research at all, and in many medical educations CAM is not represented.

The non-medical sector of CAM provision is even less represented in the research field, due to lack of academic backgrounds and interests of the providers, but also due to scientific biases and inaccessibility of funds for non-mainstream treatment methods and provisions. Research in this area has to be pushed further by the interested parties – CAM research does not happen on its own. Programmes have to be pressed into existing schedules, because existing schedules still not pay attention to the CAM field, as if it would not be part of medicine.

CAMBrella has proven that the European research network functions well and has achieved a sustained organisational level – but still with a strong bias for the Western Euro-

pean countries, and a lack of representative presence of Eastern and Southern European countries. The present CAM scene in Europe is – with the start given by the CAMbrella findings – prepared to go on. CAMbrella will support this process by maintaining the network structure, including the website as a central platform for information and communication. An essential starting point for any future research will be the proposal for a research roadmap to be published soon by CAMbrella WP7 group.

Acknowledgement

We hereby would like to thank Dr. Jürgen Clausen from the ‘Karl und Veronica Carstens’ Foundation for providing us with information on CAM research centres within Germany, Austria and Switzerland. We also thank the ‘Forum universitärer Arbeitsgruppen für Naturheilverfahren und Komplementärmedizin’, which supplied valuable contacts.

Disclosure Statement

This project was funded as part of CAMbrella Work Package 8 FP7-HEALTH-2009–3.1–3 (Grant No. 241951).

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