
V. INVITATIONAL SEMINAR ON
INFORMATION AND INFORMED
CHOICE IN THE USE OF
COMPLEMENTARY AND
ALTERNATIVE HEALTH CARE
WITH RESPECT TO
PRACTITIONERS , USERS ,
AND THE HEALTH SYSTEM

Seminar report by Theodore de Bruyn

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The views expressed in this paper are those of the seminar participants and the report author and do not necessarily reflect those of the Health Systems Division, Health Canada.

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EXECUTIVE SUMMARY

On November 20, 2000, the Health Systems Division, Health Canada, convened an invitational seminar on information and informed choice in the use of complementary and alternative health care with respect to practitioners, users, and the health care system.

The seminar brought together representatives of selected national complementary and alternative professional associations, selected national mainstream professional associations, selected national voluntary organizations providing information on complementary or alternative health care with regard to specific conditions or diseases, selected organizations providing information on complementary or alternative health care to the interested public, and staff from the Health Systems Division.

Participants noted that users of complementary and alternative health care typically ask several basic questions about a therapy or product:

- What is it?
- Will it work?
- Where can I get it?
- How much will it cost?
- Who will pay for it?

Answering these questions is harder than asking them. The information may not be available. Different sources of information may present

different or conflicting views. The level of language may be hard to understand. There may be no consensus on the basis for the claims made. Users may be unfamiliar with systems intended to assure professional competency, and these systems may be inconsistent from one jurisdiction to another. Traditional avenues for obtaining information and making decisions, such as consultation with a primary health care provider and referral to appropriate specialists, are not developed or accepted with regard to complementary and alternative health care.

Participants in the seminar contributed numerous observations and suggestions on the themes of terminology and language; sources of information; modes of communication; evidence; professional competency; and relationships with and within the health care system. While the seminar did not—and was not intended to—arrive at consensus on these themes, it did highlight some of the main issues and identify specific steps that might be taken to address these issues.

The seminar reinforced the recognition that providing information to users and enabling them to make informed choices requires a systemic approach, with continuing development and activity in a number of sectors: information systems, professional regulation, research, policy development, and consultation.

INVITATIONAL SEMINAR ON INFORMATION AND INFORMED CHOICE IN THE USE OF COMPLEMENTARY AND ALTERNATIVE HEALTH CARE WITH RESPECT TO PRACTITIONERS, USERS, AND THE HEALTH SYSTEM

INTRODUCTION

On November 20, 2000, the Health Systems Division, Health Canada, convened an invitational seminar on information and informed choice in the use of complementary and alternative health care (CAHC) with respect to practitioners, users, and the health care system.

The seminar brought together representatives of selected national complementary and alternative professional associations, selected national mainstream professional associations, selected national voluntary organizations providing information on complementary or alternative health care with regard to specific conditions or diseases, selected organizations providing information on complementary or alternative health care to the interested public, and staff from the Health Systems Division.

INVITED PARTICIPANTS

PROFESSIONAL ASSOCIATIONS

Acupuncture Foundation of Canada Institute
Ayurvedic Medical Association
Canadian Chiropractic Association
Canadian Massage Therapist Alliance
Canadian Naturopathic Association
Canadian Nurses Association
Canadian Pharmacists Association
Canadian Physiotherapy Association
Canadian Public Health Association
College of Family Physicians of Canada
National United Professional Association of Trained Homeopaths

VOLUNTARY HEALTH ORGANIZATIONS

The Arthritis Society
Canadian Cancer Society

ORGANIZATIONS PROVIDING INFORMATION

CAMline
Consumer Health Information Service

The objectives of the seminar were:

- to register the views of selected professional associations and national voluntary organizations on information and informed choice in the use of complementary and alternative health care;
- to inform activities to be undertaken by Health Canada on issues raised by the use of complementary and alternative health care; and
- to begin a dialogue among associations representing mainstream and complementary or alternative professionals on issues related to complementary and alternative health care.

There were two parts to the seminar. The seminar opened with a roundtable, during which participants were invited in turn to describe their organization or profession and identify some of their concerns with regard to information and informed choice. This was followed by small group discussions, when participants were asked to discuss the central issues thematically and identify one or two key challenges with regard to those issues.

WHAT USERS WANT TO KNOW

A note on language

The seminar addressed issues of information and informed choice in the context of the Canadian health care system. This report uses the phrase "complementary and alternative health care" because "health care" has broad systemic connotations. Other phrases used by participants included "complementary and alternative medicine", "complementary or alternative therapies", and "natural health products". The phrase "complementary and alternative health care" implies a relation to the dominant or prevailing form of health care, which in Canada is Western health care. In order to capture both the prevailing status of Western medical health care and its capacity to incorporate components of complementary and alternative health care, this report uses the term "mainstream" to refer to Western health care practices and practitioners.

As a point of reference for its discussions, the seminar asked: What do users want to know about complementary and alternative health care? Users typically ask several basic questions about a therapy or product:

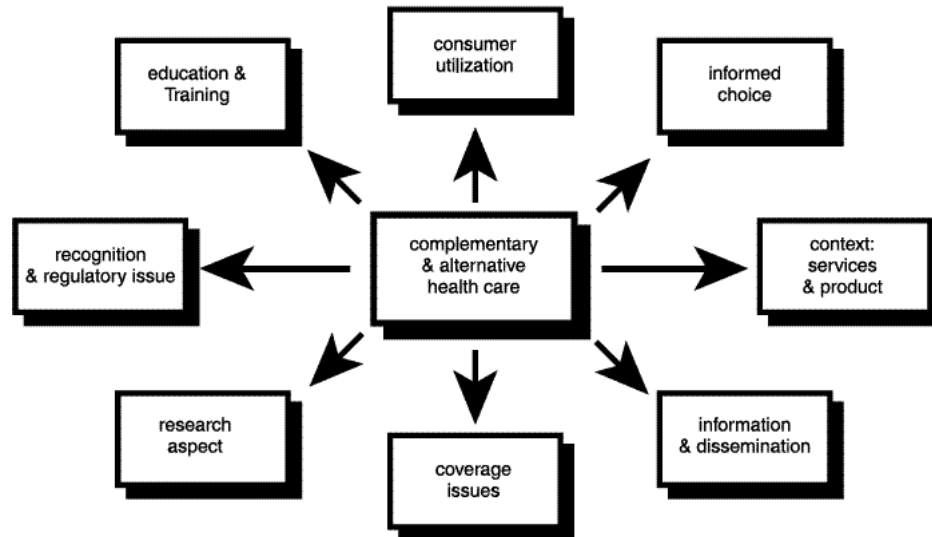
- What is it?
- Will it work?
- Where can I get it?
- How much will it cost?
- Who will pay for it?

Participants in the seminar considered what would be required to be able to answer these questions easily, clearly, and systematically. The discussion centred on a number of topics or themes, around which this report is organized: terminology and language; sources of information; modes of communication; evidence; professional competency; and relationships with and within the health care system.

These topics may be viewed as "building blocks" toward providing information to users and enabling them to make informed choices on the basis of that information. While the focus of the seminar was on how these "building blocks" would contribute to information and informed choice, the discussion showed once again that increased availability and use of complementary and alternative health care has an impact on all dimensions of the health care system (see Figure 1).

This report provides a summary of the discussion of the "building blocks". The summary is not meant to represent consensus, since the seminar was not designed to achieve this. Rather, it gathers comments made throughout the seminar with respect to the "building blocks", and organizes them under four headings: statement of the issue, observations, practical suggestions, and challenges.

Taking Stock.....



TERMINOLOGY AND LANGUAGE

Statement of the issue

Those who provide information about complementary and alternative health care find that the lack of uniform terminology and plain language is a barrier, for practitioners and providers of information as well as for users.

Observations

Many participants observed that it would be helpful to have widely accepted terminology, definitions, and descriptions of practices and products. However, the development and acceptance of terminology, definitions, and descriptions requires a process whereby practitioners come to agreement both within a profession and between professions. Several participants noted that their professional association had developed or was working toward a uniform definition of practice across Canada.

Terminology and language has implications beyond clarity of information and ease of understanding. How a practice is defined or described may have implications for utilization and coverage. For instance, users may be more inclined to use a practice that is classified as "mainstream" than a practice that is classified as "alternative". Similarly, insurers may be more ready to insure a practice that is classified as "physical manipulation" than a practice that is classified as "mind-body-spirit".

Practical suggestions

Participants offered several suggestions about how to improve consistency and clarity in terminology and language:

- develop a standardized classification system for complementary and alternative health care;
- develop a definition and description for each practice and product;
- create a glossary of terminology;
- develop "plain language" resources in Canada's official languages and in other languages, as required by the demographics of use.

Challenges

One of the challenges in developing the resources listed above is arriving at agreement on definitions and descriptions of practices and products. This is often an iterative process. It may be necessary to come to agreement on what is unique about a particular therapy, about differences of meaning in language used to define or describe the therapy, and about what various practitioners hold in common about the therapy. Government at various levels can assist by convening broad-based meetings of practitioners to work toward common terminology, definitions, and descriptions.

SOURCES AND MODES OF INFORMATION

Statement of the issue

Users of complementary and alternative health care need easy access to information they can understand from sources they can trust. In reality, users, practitioners, and providers of information are faced with multiple sources of information, some of it confusing and conflicting, without clear ways to assess the source.

Observations

In the absence of widespread knowledge and consensus about complementary and alternative health care, how are users to assess sources of information about such care? Participants noted that it helps if the source has the "stamp of approval" of a recognized authority, such as a professional association or a government agency. However, a "stamp of approval" inevitably implies criteria or "filters" by which the source and its information is assessed. This itself can be problematic when the form of health care is not widely recognized or understood.

The growth of information provided on the internet, as well as increasing use of the internet to obtain information, is both a blessing and a curse. On the one hand, users have easy access to far more information than could be obtained in print. On the other hand, users need some way of sorting through and evaluating all the information.

There is concern about the risks involved in providing information in the absence of professional advice or widespread professional consensus. Providers of information often include disclaimers about the information they provide. However, it is one thing to provide a disclaimer, another to act on it. Users may ignore or discount disclaimers, particularly when their condition or illness is serious.

Practical suggestions

Participants made a number of suggestions about how to assist users in assessing sources of information.

- There are standard criteria for assessing a source of information, such as currency, authority, disclosure, credibility of the source, etc.
- There are interactive tools to help users judge the quality of information on health internet sites (eg., DISCERN, at <http://www.discern.org.uk>; the code of conduct and checklist of Health on the Net at http://www.hon.chi/HONcode/HONcode_check.html; the IQ tool of the Health Summit Working Group at <http://hitiweb.mitritek.org/iq/about/iq.asp>; QUICK, a checklist of the Centre for Health Information Quality at <http://www.quick.org.uk>);
- Users' trust is built by a chain of sources, which collectively contribute to the completeness, accuracy, and reliability of the information sought.
- There could be an ombudsperson or a similar agency to receive complaints about adverse experiences.
- Professional associations in complementary and alternative health care have a responsibility to correct misinformation about products and practices.

Whatever the source of information, it should be available in a variety of modes in order to be accessible to a wide range of users. These include pamphlets distributed in offices, resource materials in libraries, oral information from 1-800 numbers, pages on the internet, and professional referrals. In each of these modes, information should be provided in plain language, in both official languages, and at varying levels of detail.

Challenges

Users commonly rely on two networks for information about health issues and health care: the informal network of family and friends, and the formal network of professional referral. Two challenges were noted in this regard:

- how to connect the informal network with credible information about complementary and alternative health care? and
- how to improve communication between mainstream and alternative practitioners, so that the

mainstream professional network is better able to provide information and make referrals pertaining to complementary and alternative health care?

Since users are obtaining information without necessarily consulting a competent practitioner or paying close attention to disclaimers or advisories, it may be necessary to develop a system of evaluating information according to the level of risk entailed in acting on the information. For example, information could be provided with an accompanying indication (eg., a scale of 1 to 5) of level of risk, quality of evidence, and standards of practice.

EVIDENCE

Statement of the issue

Discussions about information regarding complementary and alternative health care almost inevitably lead to discussions about the evidence on which the information is based, raising such questions as:

- What is the evidence for the effectiveness of the product or practice?
- What counts as evidence?
- What evidence is stronger than other evidence?

What makes these questions hard to answer is the fact that they arise in a context of transition. Increasing availability and use of complementary and alternative health care, as well as other trends, are having an effect on the prevailing paradigm of health, illness, and health care. As that paradigm changes, so does the paradigm for gathering, interpreting, and evaluating evidence.

Observations

Participants made various observations about what evidence is needed:

- evidence of safety and efficacy;
- evidence of benefits and harms;

- evidence of outcomes;
- evidence with regard to health promotion (wellness) and disease prevention as well as treatment.

Participants also made observations about how evidence should be defined. Some suggested that the categories of evidence should be more flexible. They should include, for example, experiential evidence as well as scientific evidence; evidence gathered within different cultures or paradigms of health (eg., evidence in China regarding traditional Chinese medicine or in India regarding Ayurvedic medicine); or anecdotal evidence and non-traditional evidence.

Participants noted that it is important to recognize that there is a range of evidence for mainstream health care as well as for complementary and alternative health care. Clearer recognition and discernment of the levels of evidence at work in all areas of health care would contribute to a more even "playing field" for all forms of health care. It was further suggested that the development of a sufficient base of evidence should be regarded as an evolutionary process (not an "either/or" dichotomy), and that it is possible and useful to distinguish levels of evidence within this process or continuum. For instance, CAMline

(www.camline.org) has set up a process to distinguish between four levels of evidence for the uses of a product: likely effective; possibly effective; further research required; and likely ineffective.

Practical suggestions

Participants suggested that it would be helpful if government, researchers, policy-makers, professionals, and consumers agreed on principles of acceptable evidence across all disciplines, and developed criteria for levels of evidence with regard to a practice or a product. Only after there was agreement on what evidence should be accepted and the criteria according to which evidence could be ranked would it be appropriate and possible to evaluate the quality of the available evidence at each level.

Suggested components of a process to agree on principles of acceptable evidence and criteria for levels of evidence were:

- a background discussion paper;
- a meeting of a broad cross-section of health professionals and researchers;
- a consensus-building process;

- public education about evidence (kinds of evidence, levels of evidence, quality of evidence).

Challenges

Participants recognized that the process of agreeing on principles of acceptable evidence across all disciplines, developing criteria for levels of evidence, and evaluating the quality of evidence at each level would itself be a challenge.

Participants also underscored the need for more broadly based research. The Canadian Institutes of Health Research has a key role in this regard, both in broadening the base of research to include complementary and alternative health care and in recognizing a greater range of evidence for health care in general.

At the same time, it was noted that the paradigms for some forms of complementary and alternative health care are incomparable to or incompatible with the paradigm of Western scientific medical care. This complicates the task of defining, obtaining, evaluating, and validating evidence for these forms of care.

PROFESSIONAL COMPETENCY

Statement of the issue

Users want to know that health care practitioners are qualified and competent to provide information, advice, and care. It is difficult for them to ascertain this with regard to (some forms of) complementary and alternative health care, for a number of reasons:

- lack of information about professional qualifications;
- lack of information about professional associations;
- lack of recognition within the health care system of professional qualifications and practice standards of alternative practitioners;

- variability and inconsistency in legislated regulation from one province/territory to another;
- confusion about the difference between practice standards and legislated regulation.

Observations

To increase users' knowledge of and confidence in practitioners, several participants in the seminar favoured a competency model comprised of the following components:

- the same standard of training, certification, and practice for all practitioners (mainstream or alternative) of a given therapy;

- recognition of professional qualifications and practice standards for a given therapy throughout the health care system;
- legislated regulation of a practice only when warranted by the potential risk of harm;
- public education regarding the distinction between practice standards and legislated regulation.

Who is responsible for the development and implementation of practice standards? Several participants stated that the primary responsibility lies with the practitioners themselves. This requires significant human and financial resources, which some alternative professional associations may not have. Nevertheless, voluntary regulation of practice standards is considerably less expensive than legislated regulation.

It is helpful to both users and practitioners if professional qualifications and practice standards are consistent in all jurisdictions in Canada and internationally. In the absence of uniformity, users are confused about competency. Unfortunately, the current status of legislated regulation for all but a few forms of complementary and alternative health care is variable and inconsistent across the provinces and territories. Several participants argued for regulatory reform and public education to establish a more coherent and consistent regime which differentiates appropriately between practice standards and legislated regulation (the latter only required by potential risk of harm).

Practical suggestions

In the absence of uniform and recognized professional qualifications and practices standards, users might be provided with a check-list of items to investigate with regard to a new or unfamiliar practice:

- Is there a standard certification for the practice and, if so, what is it?
- What is required for professional certification?
- Is there a professional association?

- Is there a regulatory association?
- Is the regulation of the profession voluntary or legislated?
- What are the scope of practice and the standards of practice for the profession?
- Is there someone to notify or inquire about adverse experiences?
- Where can one obtain further information?

There are several ways in which government at various levels can assist or provide leadership, by:

- convening national meetings on practice standards that are inclusive and respectful;
- preparing a competency profile for a particular profession or practice;
- preparing a labour market/occupational profile for a profession;
- negotiating terms for labour mobility across jurisdictions; and
- educating the public about competency (professional qualifications, practice standards, legislated regulation, etc.).

Challenges

Participants observed that the success of a competency model based on practice standards depends on widespread recognition of the legitimacy of the practice. It is essential that discussions about a practice be inclusive and respectful. In the absence of such recognition, alternative practitioners seek legislated regulation in order to gain professional legitimacy. Often the process of obtaining legislated regulation is fraught with competition and strife both within the profession and with other professions. It is also costly in human and financial resources.

While the deficiencies of the current regulatory regime were apparent to participants, they also recognized that regulatory reform is a challenging, long-term process. It will require on-going discussion

within federal/provincial/territorial structures. There are models, such as the regulatory regime adopted by Ontario, that may serve to establish a more coherent and consistent system across Canada for complementary and alternative health care. But the division of responsibilities between the federal

government, which regulates products, and the provincial/territorial governments, which regulate practices and practitioners, necessitates continuing communication and collaboration between levels of government on regulatory matters.

RELATIONS WITH AND WITHIN THE HEALTH CARE SYSTEM

Statement of the Issue

Relationships between complementary and alternative health care practitioners and the mainstream health care system are in a state of transition. Some practitioners have achieved a degree of recognition within the mainstream system and have established relationships with mainstream practitioners. Others have not. Some are endeavouring to achieve greater recognition and establish better relationships. Others are not. And the mainstream health care system, itself complex and varied, is more or less receptive to new relations with complementary and alternative practitioners

In this state of transition it is not possible to pre-determine the ideal relationship between complementary and alternative health care and mainstream health care. While integration within the mainstream health care system may be desirable and appropriate for some forms of complementary and alternative health care, for others it is not.

Nevertheless, users rely on practitioners, mainstream as well as alternative, to provide information and to refer them to qualified specialists, as required. When there is no recognition within the mainstream health care system of a form of complementary or alternative health care, and no established relationships among practitioners, users may not seek or obtain the information they require from practitioners.

Observations

Participants noted that the reality at present is a degree of interface between mainstream and

alternative practitioners in some areas of care. This may involve sharing information, patient referral, and combinations of therapies. Participants in the seminar noted several difficulties in this regard.

First, the initiative tends to be one-sided, initiated perhaps by complementary and alternative practitioners but not vice versa. Moreover, discussions between mainstream and alternative practitioners can become acrimonious, manifesting a lack of respect for practices that do not fit into the paradigm of Western scientific medical care.

Second, a private-sector model for the delivery of professional services does not facilitate integration, since various practitioners may be competing to perform the same services. Complementary and alternative health care practitioners are concerned about mainstream practitioners providing services that CAHC practitioners are more qualified to provide but for which they have less recognition (colloquially referred to as "raiding"). Mainstream practitioners are concerned about the allocation of public resources and the need for cost/benefit analysis before adding more publicly funded services.

Third, insurance coverage, in addition to helping users to pay for a therapy, is an important "cue" regarding its recognition. As several participants noted, coverage influences recognition and utilization, and vice versa. However, the variable interface between complementary and alternative health care and mainstream health care is reflected in insurance coverage (public insurance, private insurance, and rehabilitation insurance). Some complementary and alternative practices and products are covered, whereas others are not.

Whether a therapy is covered may depend on where the service is provided (eg., it may be covered in a hospital, clinic, or doctor's office, but not as a free-standing service) and who is providing the service or making the referral.

Practical suggestions

Participants observed that greater recognition for complementary and alternative health care will develop in tandem with approved sources of information, criteria for evidence, practice standards, and regulation. There were several suggestions as to how government at various levels might facilitate the process:

- Develop a vision for integrated health care, including guiding principles such as a holistic approach to health, freedom of access, universal standards of practice, regulation of potential harms, and effective and cost-effective allocation of public resources. A vision for integrated health care may have to accommodate forms of health care that cannot be integrated or do not wish to be integrated. In spite of this, it is important to have a comprehensive view of relationships between complementary and alternative health care and the health care system.
- Level the "playing field" by including alternative practitioners, information providers, and users of complementary and alternative health care, as well as mainstream practitioners, in policy discussions (as, for instance, in the seminar being reported here). This will require pro-active measures on the part of governments and research

institutes to improve communications, build capacity for engagement, foster knowledge and understanding (if not agreement) among parties to the discussion, etc.

- Put specific issues related to complementary and alternative health care on the agenda of federal/provincial/territorial structures, in consultation with alternative practitioners, mainstream practitioners, information providers, and users of complementary and alternative health care;
- Include complementary and alternative health care in national discussions about changing medicare or introducing pharmacare.

Challenges

Participants acknowledged that developing a vision for an integrated health care system, and working toward the achievement of that vision, will be difficult because of the complexity of the system, the various approaches to health and health care, and the diversity of views on the merits or feasibility of integration. Progress may be easier and quicker in other areas than in this one. Nevertheless, work on an integrated health care system should continue in parallel with work on other fronts. It remains an important "building block", in so far as it encourages a comprehensive approach to relationships with and within the health care system. In fact, the Health Systems Division has already begun exploring issues related to a more integrated health care system in several discussion papers.^{1 2}

¹ Advisory Group on Complementary and Alternative Practices and Therapies. "Towards an Integrative Health System: draft Discussion Paper from the Advisory Group on Complementary and Alternative Practices and Therapies." Health Systems Division, Health Canada, February 2000.

² James T. Casey and Frances Picherack. "The Regulation of Complementary and Alternative Health Care Practitioners: Policy Considerations" Health Systems Division, Health Canada, March 2001

