THE NACA POSITION ON
DETERMINING PRIORITIES IN HEALTH CARE:
THE SENIORS' PERSPECTIVE

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National Advisory Council on Aging

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WHAT IS THE NATIONAL ADVISORY COUNCIL ON AGING?

The National Advisory Council on Aging (NACA) was created by Order-in-Council on May 1, 1980 to assist and advise the Minister Health on issues related to the aging of the Canadian population and the quality of life of seniors. NACA reviews the needs and problems of seniors and recommends remedial action, liaises with other groups interested in aging, encourages public discussion and publishes and disseminates information on aging.

The Council has a maximum of 18 members from all parts of Canada. Members are appointed by Order-in-Council for two- or three-year terms and are selected for their expertise and interest in aging. They bring to Council a variety of experiences, concerns and aptitudes.

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NACA BELIEFS

NACA believes that:

- Canada must guarantee the same rights and privileges to all its citizens, regardless of their age.

- Seniors have the right to be autonomous while benefitting from interdependence and to make their own decisions even if it means 'living at risk'.

- Seniors must be involved in the development of policies and programs and these policies and programs must take into account their individuality and cultural diversity.

- Seniors must be assured of adequate income protection, universal access to health care, and the availability of a range of programs and services in all regions of Canada that support their autonomy.

THE NACA POSITION IN BRIEF

Canada has developed a health care system that provides comprehensive and universally accessible care to all residents. However, choices among health care services will have to be made if the health care system is to remain affordable as well as universal. Decisions regarding health care priorities should be guided by consistent principles and should meaningfully involve all persons who are affected by health care decisions, including seniors.

The National Advisory Council on Aging (NACA) consulted health economist Douglas Angus and major seniors' organisations with the aim of establishing principles to assist in distinguishing essential from non-essential health care services. In developing its position, NACA considered the ethical principles involved in the distribution of public resources and the levels at which health care decisions are made.

In considering the availability and quality of health services, NACA examined the distribution of resources to health promotion in relation to health care, issues pertaining to the effectiveness and efficiency of health care services and the regionalization of health care decision-making.

1. With respect to the distribution of resources to health promotion in relation to health care, NACA recommends that:

The federal government allocate resources to develop effective, ongoing collaboration among departments whose activities impinge on the health status of Canadians in order to strengthen the social, educational, economic and environmental determinants of health.

Provincial and regional governments establish intersectoral coordination among ministries or service sectors concerned with the health and well-being of the population.

Health Canada, provincial/territorial ministries of health, regional health councils and health care institutions accord a higher priority than at present to promoting the health of the population.

The federal government, through the National Forum on Health, consult with the Canadian population at large to determine how individual freedom should be weighed in relation to health status in designing measures to promote and protect the health of the population.

2. With respect to improving the effectiveness and efficiency of the health care system, NACA recommends that:

Provincial/territorial governments continue to fund research that evaluates the effectiveness and efficience of health services and products and to link the allocation of resources for existing and proposed services to the research findings.

Any proposed determination of priorities among health care services based on cost-effectiveness considerations be submitted for open discussion by all stakeholders, including seniors and their organizations to achieve common agreement on priorities and to avoid discrimination.

The provinces/territories make available alternative health care practitioners where appropriate and cost-effective.

The provinces/territories encourage the public through educational campaigns to use the services of the least-costly qualified health care providers and promote interdisciplinary partnerships among health care practitioners.

3. With respect to the regionalization of health care decision-making, NACA recommends that:

The federal and provincial/territorial governments and stakeholder groups determine the core health services and quality standards to be provided across Canada, and devolve responsibility for services beyond the minimum to local health authorities.

In considering the accessibility of health services, NACA considered the matter of public and private access to care, the methods by which health services are remunerated, the ways in which health care practitioners determine access to limited services and the extent and limits of patient choice in health care.

4. With respect to the question of public and private access to health care, NACA recommends that:

The federal and provincial/territorial governments diligently maintain a single-tiered system of universal access to essential health services.

5. With regards to the reimbursement schemes for health care practitioners, NACA recommends that:

Provincial/territorial governments adopt methods of reimbursing physician services that combine salary or capitation with fee-for-service to encourage the provision of medical care that is both cost-effective and meets individual needs.

6. With respect to the ways in which health care practitioners determine access to limited services, NACA recommends that:

Decision-makers at the meso level develop criteria for access to health services by means of clinical guidelines or practice protocols and monitor their application by individual practitioners.

The federal government and provincial/territorial governments give high priority to the wide dissemination of knowledge on best clinical practices through the Canadian Institute of Health Information.

Professional associations and health care institutions establish continuing education programs, peer review committees, external practice audits and other methods proven effective both to keep health care practitioners up-to-date with the evidence on the effectiveness of services and to modify their clinical practice accordingly.

7. With regards to the patient's right to decide his or her access to specific health services, NACA recommends that:

All factors influencing a patient's capacity to benefit from health services, including social supports, be taken into consideration in assessing the benefits and risks of treatment options.

Health services be provided only in accordance with a patient's free and informed consent, based on his/her values regarding the quality of life.

Measures that enhance an individual's capacity to make self-determined decisions regarding health care be legally recognized and widely implemented.

Ethics committees monitor the use of advance directives, living wills and power of attorney for personal care to ensure that their purpose is not subverted to deny legitimate treatment to individuals in need of care.

Individual and family requests for access to health services deemed by the treating professional(s) to yield only marginal benefits be considered by independent committees of professionals and ethicists who would evaluate the request based on evidence of the potential benefits in relation to the potential costs.

8. Finally, NACA addresses the need for open communication among decision-makers and stakeholders and the responsibility of citizens for participating in the decisions regarding the distribution of health care resources. NACA recommends that:

All Canadians demand full and clear information from federal, provincial/territorial and local health authorities on health issues that affect them and their communities and actively participate in the consultations that lead to decisions about health priorities.

THE NACA POSITION ON DETERMINING PRIORITIES IN HEALTH CARE: THE SENIORS' PERSPECTIVE

INTRODUCTION

Over the last 30 years, under the leadership of the federal government, Canada has developed a publicly administered system of comprehensive and universally accessible health care services. Canada's health care system is a source of pride for Canadians and a cherished symbol of the values of equity and compassion that are intrinsic to our national identity. Justifiably, the great majority of Canadians-the National Advisory Council on Aging (NACA) included-are committed to continuing this system now and in the future.

Nevertheless, the costs of maintaining the health care system have been rising steadily, more than doubling since 1971.[1] At the present time, Canada spends about $68 billion per year on health care, or about 10% of the Gross Domestic Product. Indeed, of all the industrialized countries which have predominantly publicly funded health care systems, Canada spends the most per person for health care services. The provinces and territories feel the burden of health care costs most acutely: health care is the largest single expenditure in their budgets, ranging from 24% of the budget in Newfoundland to 38% in Saskatchewan.[2] As necessary as health is, money spent on health care is money lost to other sectors that contribute to the well-being and prosperity of Canadians.

Although the *Canada Health Act* (1984) never suggested that universal health care insurance should provide all medical and hospital services to all Canadians, many people have come to believe that there is a promise to do so. For most of Canada's history under public health insurance, more resources have been added to the system to cover more, and increasingly sophisticated and expensive, services. However, as

the federal and provincial governments grapple with growing fiscal constraints and pressures on their capacity to deliver a wide range of public services, they are searching for ways to provide health care more efficiently and effectively, but still equitably.

Reducing inefficient and ineffective spending will help stretch the health care dollar further, but it will not be enough. Choices among health services will have to be made if the health care system is to remain affordable as well as universal.[3] In assigning priorities, it is inevitable that some 'desirable' services will have to be denied: alternatives with low priority must be traded off for higher priority alternatives.

Determining priorities for health care is not easy. But it is essential. How should these decisions be made? Who will make them? To be sure, a variety of information-gathering and analytical techniques can be used, but scientific analysis can only inform decision-making. Because decisions on allocating public resources bear on fundamental moral values, such as justice, compassion and liberty, they are ultimately moral issues.[4] Issues of public morality must be resolved by involving all people who have a stake in the issues. They must be allowed to shape decisions, based on the values they consider more important. The alternative is to make allocation decisions based on motives that may be contrary to the common good, such as yielding to powerful private sector lobbies like manufacturers of high-technology equipment, special interest groups or media-driven sympathy for individuals with special and costly needs.

When the Honourable Diane Marleau, Minister of Health, requested advice, NACA consulted Douglas Angus, a health economist, and major seniors' organizations with the aim of establishing principles to assist in distinguishing essential from non-essential health care services. Representatives from national and provincial seniors' organizations and from provincial councils attended a one-day workshop

organized by the Council to present their views on the principles that should underlie priority-setting in health care. Because seniors remember Canada prior to the development of its public health system, they have an important and unique role to play in any discussions regarding health care reform. NACA's position on determining health care priorities is informed by the views that seniors expressed at the workshop; throughout this report, views expressed at the workshop are quoted to highlight major points. As well, this report benefited substantially from the analyses of health economists and ethicists, especially those of Douglas Angus[5] and Michael Yeo.[6]

1. ALLOCATION PRINCIPLES

> "An approach to allocation should begin with a value-driven system that is decided collectively."

Ethicist Michael Yeo[7] points out that in making decisions that require distributing resources and making trade-offs, two lines of moral reasoning are pertinent: What criteria should be used to decide what constitutes a fair distribution? and, What process should be applied to reach fair decisions? The first question refers to the substantive (or content) principles of justice and the second concerns the procedural (or process) principles of justice. In determining priorities in health care, the substance of the decisions and the process of decision-making are equally important.

According to Yeo, four relevant substantive principles can be used to determine health care priorities: need, equality, utility and liberty.[8]

Need: A health need is a requirement for some resource necessary to restore or maintain life or quality of life. The condition of human need creates an obligation to respond. In the context of health care, this principle requires that resources be allocated in proportion to health needs: the

greater the need, the more resources. When there are more needs than can be met (e.g., a busy emergency room), the greatest and most urgent should have priority.

Equality: The belief that every person is as important as anyone else leads to the principle of equality; that is, everyone should receive the same treatment. With respect to health, equality can mean equal access to health care services, and it can mean equal health status. People with equal needs should be treated similarly, without discrimination on the basis of factors unrelated to health, such as age, sex, income, ethnic origin or place of residence. For instance, if an 80-year-old and a 50-year-old person need a heart-transplant, both should receive it.

Utility: According to this principle, one should strive to achieve the greatest benefit for the greatest number of people. Thus, in health care, the priority should be to provide services that offer the most benefit to the most people. An example might be immunizing all children in a community against influenza instead of giving a few persons renal dialysis.

Freedom: People have freedom when they can make choices affecting themselves without interference from others. In Canadian health care, this principle currently entitles people to choose their physician (or an alternative health care practitioner for some services in some provinces) or to refuse the treatment recommended.

When making decisions about health care, these substantive principles must be weighed against one another in terms of their consequences. Canada's health care system has until recently placed emphasis on the principles of need and equality. Increasingly, however, the fiscal constraints have given the principle of utility greater

prominence. Will a greater emphasis on utility mean that individual needs may not be met, or that access to services will become less equal? Fears that cut-backs to a common health care system will mean erosion of quality (and poorer working conditions and remuneration for providers) have led to demands for greater personal freedom, both by health care providers who want to provide their services outside of provincial health insurance plans and by consumers who want the option of going to private clinics. Will equality be threatened by allowing greater individual freedom for consumers and providers in health care? There is no pre-set formula to set priorities among these principles: it is the process by which dominant values are selected which is critical to achieving a just outcome.

In a democratic society, the following three principles guide the process by which decisions regarding the allocation of public resources are made.[9]

Explicitness: The substantive principles upon which decisions are to be based and the process by which decisions are made must be explicit and open to public scrutiny.

Accountability: Those entrusted to make decisions must be accountable for the decisions they make.

Autonomy: People are entitled to participate in making decisions that directly affect them, or in which they have a stake; the greater the stake they hold, the greater their participation should be.

Adoption of these principles ensures that the process of deciding among priorities in health care is as fair as it can be; it also helps to build collective support for the choices that are made.

2. LEVELS OF DECISION-MAKING

The problem of allocating health care resources arises at three different levels of decision-making. Different substantive principles may be appropriate at these levels, but the process principles described above remain the same.

At the broadest--macro--level, the emphasis is on allocating resources to the health care system as well as other public sector priorities, such as employment, transportation and education. These government policy decisions take place within the federal and provincial/territorial cabinets. At another level of macro decision-making within federal and provincial/territorial departments or ministries of health, or regional health councils, decisions are made with respect to the allocation of resources within the health system. It is here that issues arise regarding the appropriate amount of resources to distribute to acute-care hospitals, community health services, drugs and so on.

The intermediate--meso--level of decision-making occurs within institutions, hospitals or community agencies. At this level, decisions are made with respect to the distribution of resources that have been received from the ministries of health. For instance, hospital boards decide how much of their global budget to allocate to out-patient surgery, diagnostic services, rehabilitation, geriatric units and so on.

The lowest--micro--decision-making level involves the individual health care provider and the patient. Here, decisions revolve around concerns as to whether or not a particular patient will receive a given service and which individuals will have access to resources that are available in limited supply. Examples include establishing priorities for patients awaiting bypass surgery, hip replacements, cataract removal and so on.

The three levels of decision-making are distinct and involve different decision-makers and stakeholders. At the macro and meso levels, decisions concern the *availability and quality* of services, while at the micro level, decisions pertain to access to health services. At the macro level, politicians and/or bureaucrats make decisions regarding the allocation of resources to and within the health care system with varying degrees of input from stakeholders, including health care professionals, other health care interests and the public. At the meso level, decisions and priorities are generally made by Boards of Trustees, administrators and managers working in collaboration with health care professionals; stakeholder groups include the health care professions and the local residents. Finally, at the micro level, physicians usually have the main prerogative for decision-making, although increasingly, other health care professionals are providing valuable input during the decision-making. The stakeholders here are obviously the individual patient and his/her family.

While these levels of decision-making have been discussed separately, in fact all are interconnected. This is clearly one of the challenges of decision-makers. For instance, the amount of money a government budgets for health care determines how much money is available for hospitals, health centres, physician services, drugs, etc. The money available for each of these areas then puts a limit on how much is available for seniors within each area. This limit to the availability of services in turn establishes ceilings on the degree of accessibility of those services to individuals in need in the community. Thus, eventually, decisions made at the "top" make their way down to the frontlines of the health care system, where services and treatments are provided to (or withheld from) some (but not all) individuals.

3. AVAILABILITY AND QUALITY OF HEALTH SERVICES

3.1 Health versus Health Care

"Health is more than health care: it is also housing, transportation, income security and a healthy environment."

"At the regional level, there should be coordination between health, housing and social planning councils."

NACA has adopted a global perspective that defines health as a key resource for living, involving an equilibrium with one's environment and with one's physical and mental strengths and limitations.[10] Consistent with this broad understanding of health, the *Canada Health Act* (1984) states, "The primary objective of Canadian health care policy is to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health care without financial or other barriers."[11]

Nevertheless, it has become evident that far greater emphasis at all levels of decision-making has been placed on restoration than on protection and promotion. Equality of access to medical and hospital services has taken precedence over the goal of 'achieving health for all'--that is, assuring the equality of health status among Canadians. Indeed, major national surveys have shown that persons with low income experience lower health status than middle and upper-income persons, despite their greater use of health care services.[12]

Health is determined by factors other than access to health services. These include income, education, environment, genetics and individual practices. Canadian health policy makers have known this for the past 20 years.[13] However, there has not yet been a sufficient allocation of public resources to protecting and preserving the

health of Canadians by enhancing the factors that determine health. This is undoubtedly a more difficult task because it requires the close collaboration of many policy sectors at all levels of government. The gains of such an approach are long-term and the tendency to give priority to immediate needs for health care services is understandably strong, particularly at the meso level of decision-making. In addition, some measures that would promote a healthy population may involve public decisions that limit individual choice or invade personal privacy: for instance, obliging people to wear seat belts, advertising methods of AIDS prevention on television or forbidding smoking in public places.

NACA believes that in allocating resources for health, greater priority than at present should be given to implementing policies that promote health as a means of achieving equality in health status among Canadians, even at the expense of individual freedom in some instances. If health protection and promotion do not assume higher priority, inequalities in health will persist and the demands for health care services may outstrip the resources available. In accordance with this position, the representatives of national seniors' organizations attending NACA's workshop stressed that, to improve the health of seniors, greater emphasis should be placed on developing a holistic 'health system' that takes into account financial security and a supportive social and physical environment rather than on continuing to expand the current 'illness system'. Hence,

NACA recommends that:

The federal government allocate resources to develop effective, ongoing collaboration among departments whose activities impinge on the health status of Canadians in order to strengthen the social, educational, economic and environmental determinants of health.

Provincial and regional governments establish intersectoral co-ordination among ministries or service sectors concerned with the health and well-being of the population.

Health Canada, provincial/territorial ministries of health, regional health councils and health care institutions accord a higher priority than at present to promoting the health of the population.

The federal government, through the National Forum on Health, consult with the Canadian population at large to determine how individual freedom should be weighed in relation to health status in designing measures to promote and protect the health of the population.

3.2 Effectiveness and Efficiency

"Wants and needs are very different concepts; you may 'want' a sedative, but you may 'need' exercise."

The notion of health need is very elastic, despite attempts to circumscribe it by using attributions such as 'medically necessary' or 'essential'. In practice, physicians define patients' needs in terms of the services they provide. The use of health services (presumed to reflect need) is heavily influenced by factors such as the number of physicians available, variations in styles of practice, the development of new technologies and the age of the patient.

The number of doctors available to serve the population influences the usage of health services: the more doctors there are, the more health services are used. Currently, Canada has an oversupply of physicians to meet health care needs,[14] although there may be an undersupply of certain medical specialists.

Wide variations among geographical areas exist in the rates of certain health services, including surgical procedures and length of hospital stays. Research shows that geographic differences in the prevalence of certain disease conditions are not sufficiently great to justify these variations in treatment practices; for instance, Canada has the highest rate of gall-bladder surgeries among Western countries, although there is a similar proportion of people with gallstones in all countries.[15] The variations in services reflect local standards of practice that are heavily influenced by the preferences of the medical leaders in each country, region, or community rather than by objective evidence of the effectiveness of different services in meeting health needs.

New needs are created by the development of new diagnostic and treatment technologies, including pharmaceutical products. There is a general uncritical belief that new technologies are always better than existing ones, and the introduction of a technology leads to a demand for its use. Nevertheless, most new health care technologies are adopted with only minimal evidence of their clinical effectiveness.[16]

With advancing age, many people develop health conditions requiring health care. However, in recent decades, the intensity of services provided to seniors has increased; in British Columbia, for instance, overall hospital rates decreased by 16% between 1969 and 1988 but increased among seniors by 14%." The increased intensity of long-term, rehabilitation and acute-care health services cannot be explained by a deterioration in the health of seniors, nor can it be justified in terms of improved health outcomes, since the rise in service use is related to conditions for which there have been no significant improvements in treatment (e.g., senile dementia cardiovascular disease).[18]

"We must do the right thing to the right people at the right time."

An approach to assessing needs and setting priorities among them is to link them with benefits.[19] A person is in **need** of a health service if he/she will gain some benefit from it. If someone is too sick to benefit from any treatment, or has a disease for which no treatment exists, or yet again, will heal just as quickly with or without health care (e.g., the common cold), this person is not in need of health care. Thus, health care can be determined by assessing how much benefit is gained by a service in terms of life extension and/or improvement of the quality of life. A beneficial service is an **effective** one.

When resources are limited, however, services also have to be assessed in terms of their efficiency as well as their effectiveness. An **efficient** service is one that provides health benefits at the lowest cost.

The Canadian health care system is frequently criticized for providing services whose effectiveness has not been demonstrated and for delivering these services with minimal consideration of cost.[20] in response to these criticisms and to the financial pressures on the health care system, much research is being devoted across Canada to identify health services that are effective, and among those that are effective, the ones that are least costly.[21] Provincial/territorial ministries of health and health care institutions, in turn, are gradually shifting the allocation of available resources away from services that have been shown to be less effective and efficient (for instance, by de-insuring certain laboratory tests for persons not considered at risk for a particular disease or by proposing to de-insure the annual routine health examination). For example, in the Netherlands, the committee on Choices in Health Care developed a model to determine health care priorities; the model includes an assessment of what is necessary care, assessments of the clinical effectiveness and economic efficiency of alternative treatments and a consideration of the extent to which individuals should be responsible for financing that care (i.e., user charges).[22]

In light of these considerations,

NACA recommends that:

Provincial/territorial governments continue to fund research that evaluates the effectiveness and efficiency of health services and products and to link the allocation of resources for existing and proposed services to the research Findings.

"Seniors are concerned about possible discrimination in health service allocation."

By stretching available resources further to give the greatest benefit to the most people, the application of the principle of utility through the economic criteria of effectiveness and efficiency is consistent with and, indeed, reinforces the principle of equality. However, there is a danger that rigid adherence to the principle of utility in health care decision-making can conflict with the value of equality. As well, the differences in effectiveness and efficiency among various services are not always clear.

In recent years, economic measures of health outcomes have been devised to compare different treatments with respect to their effectiveness in extending life and in improving quality of life. They bear names such as 'healthy-year equivalents' (HYE), 'health-adjusted life expectancy' (HALE) and 'quality-adjusted life years' (QALY). For example, economists estimate how many QALYs each service or treatment is worth, then divide the cost of the service by the number of QALYs to obtain an estimate of cost-per-QALY. A service with a lower cost-per-QALY is considered to be more cost-effective, and thus to have a higher priority in a limited array of health services than a service with a higher cost-per-QALY.

The best-known example of the use of health outcome measures to set priorities is that of the state of Oregon. Four years ago, Oregon used QALYs to establish priorities among health services in order to extend public health care coverage to persons previously ineligible for Medicaid. Legislators planned to proceed top-down, funding treatments higher on the list of priorities until the point at which the available funds were depleted; treatments below that point would not receive funding. The plan, which was never implemented, generated much discussion, both because of the extensive public consultations conducted and because of the ethical implications of the priority listing.[23]

A major difficulty with the establishment of service priorities based solely on maximizing benefits at least cost is that it can easily lead to discrimination against disabled persons and seniors. Long-term care for chronic disabilities, palliative care and many treatments for diseases common in later life obtain low QALYS, because the extension of life is limited and/or the gains in quality of life expected from these services are not as great as for other services. In NACA's workshop, seniors placed a high value on achieving greater effectiveness and efficiency in the health care system, but expressed concern that negative stereotypes about aging and seniors could lead to age discrimination in the guise of economic 'objectivity'.

Although these measures provide useful information on the cost-effectiveness of health services, the values of equality and meeting needs must balance that of utility so that setting priorities among treatments does not lead to discrimination against people with particular health needs. Also, because setting priorities involves weighing the potential benefits and harms of various service options to the whole population, all stakeholders must be meaningfully involved.

NACA recommends that:

Any proposed determination of priorities among health care services based on cost-effectiveness considerations be submitted for open discussion by all stakeholders, including seniors and their organizations, to achieve common agreement on priorities and to avoid discrimination.

"A greater case should be made for alternative or complementary types of health care."

It has been shown that many services provided by chiropractors, midwives, nurse-practitioners and nurse anaesthetists are equal to those of physicians and more cost-effective, and that family physicians can provide many services as competently and more cheaply than specialists.[24] For example, nurse practitioners have become widespread in the United States, working in areas such as general practice, geriatrics, paediatrics, family planning, psychiatry and obstetrics: studies show that nurse practitioners provide a similar quality of care as physicians, are accepted by patients in lieu of doctors and generate lower health care costs than doctors.[25] Thus, substitution of the services of an equally competent, but less expensive health service provider for physician services is recommended by health economists.

The entry of alternative health care practitioners has occurred to some extent in Canada (for instance, midwives are licenced to practice in Ontario and chiropractors are covered by health insurance in some provinces). Nevertheless, the opposition of powerful professional lobby groups has prevented further human resources substitution in the health field or collaboration between established and newer groups of health practitioners (for example, Ontario's attempts to increase the scope of duties of nurse practitioners and Quebec's efforts to allow midwifery have been fiercely opposed by physicians). To allow Canadians a wider choice among competent health care practitioners, while using limited health resources more judiciously,

NACA recommends that:

The provinces/territories make available alternative health care practitioners where appropriate and cost-effective.

The provinces/territories encourage the public through educational campaigns to use the services of the least-costly qualified health care providers and promote interdisciplinary partnerships among health care practitioners.

3.3 Universality and Regionalization

"We should not arrive at a point where the regionalization of service allocation is accompanied by a lack of a more global perspective and the loss of cross-regional services."

In the context of broad health reforms, the provinces have devolved, or are in the process of devolving or decentralizing the planning and delivery of health care to the regional level. It is believed that decentralization will allow consumers to play a greater role in allocation decisions directly affecting them and will allow for a flexible establishment of priorities in accordance with community needs. There is a danger, however, of creating disparities among regions in the type and quality of services offered.[26] NACA believes that universality in health care means that, even in a decentralized system, people in all regions should have access to a core of common services with a standard level of quality.

NACA recommends that:

The federal and provincial/territorial governments and stakeholder groups determine the core health services and quality standards to be provided

across Canada, and devolve responsibility for services beyond the minimum to local health authorities.

4. ACCESSIBILITY OF HEALTH SERVICES

4.1 <u>One Tier or Two?</u>

"The U. S. has an 'efficient' allocation based on capacity to pay, whereas Canada has developed an allocation system based on the fundamental principles of the Canada Health Act."

"The principles of the Canada Health Act are sound and should serve as the foundation of the future."

The principle of equality is expressed in the Canada Health Act through the condition of universal access; that is, all residents of Canada have (or should have) access to the same package of health care services, without financial or other barriers. Universality thus denies people who can pay privately the freedom of buying more and better services. When, as in the past, the health care system provides everyone with almost everything, this limit to individual freedom is not a major issue of contention. In recent years, the non-coverage of some services considered to be non-essential, such as surgical correction for myopia and cosmetic surgery, has led to the establishment of a private system which provides these services at personal cost. Increasingly, as waiting lists for insured health services grow, for-profit clinics are being established in some areas to offer services to people who can pay and do not want to wait. As the health care system is forced to offer a reduced package of common services, the claims for greater individual freedom at the expense of equality may become more insistent. How should these claims be evaluated?

On one hand, the growth of a second, private tier in the health care system could be advantageous to the public tier by relieving the demand for services and freeing up resources. In addition, the private system could serve as an experimental ground for new services that could be transferred to the public system as their effectiveness and efficiency are perfected. This would work, however, only if those who choose the private system continued to support the public system; if support for a common system is challenged, the quality of the system could diminish for those who do not have the option to choose. A single health care system assures equality of health care; however, it also condemns everyone to mediocre care if cost pressures lead to a general reduction in the availability and quality of care.

Excellent care for some and poor care for others, or mediocre care for everyone-is this the inevitable choice? The best solution is solidarity (that is, a common commitment to providing the best care possible, within fiscal limits, to all residents of Canada). The commitment to a universal, single-tiered system without special privileges was reaffirmed at NACA's workshop on determining priorities in health care. Thus,

NACA recommends that:

The federal and provincial/territorial governments diligently maintain a single-tiered system of universal access to essential health services.

4.2 The Dilemmas of Health Practice

Physicians and other health professionals have a primary moral duty to serve each patient to the best of their ability, with all the resources at their disposal. In practice, health professionals do weigh factors other than the benefit of a single patient in their decisions. If a health professional has to choose between helping one person or another person whose need is more urgent, he or she will meet the urgent needs

first.[27] A professional's decisions are also influenced by the expectations of the patient, of the patient's family and of other health professionals.[28] Finally, the method by which the professional is remunerated will influence clinical decision-making.

In the Canadian health care system, most physicians are paid a fee for each service they render and some services are paid more highly than others, Thus, doctors who spend less time with an individual patient and provide more reimbursable services (for instance, diagnostic tests, repeat visits, well-paid treatments) are economically advantaged. The fee-for-service scheme is one of the factors responsible for the high cost of the health care system because it encourages the provision of excess services.[29] It is also partly responsible for the problem of excessive and inappropriate medication of seniors because handing out prescriptions can be a fast way of dealing with seniors' health complaints.[30] Indeed, fee-for-service is incompatible with geriatric practice, because diagnosis and treatment of older patients is often more time-consuming. It also provides no incentives for doctors to engage in health promotion. Thus, fee-for-service may be in conflict with both the principles of utility and of meeting needs.

Alternatives to fee-for-service reimbursement have been proposed.[31] These include payment by salary and capitation (that is, paying each physician a fixed amount for each patient enroled in his/her practice). For example, in Quebec, physicians working in community health and social service centres are salaried and in the United States, doctors working in Health Maintenance Organizations (HMOS) are paid through capitation. Reimbursement by salary and capitation reduces service excess, since there is no monetary advantage to providing more services than are needed. On the other hand, these schemes could also discourage the provision of extra services in cases where more than a minimum is required. A combination of one of these alternatives with fee-for-service for special services may be the optimal solution. For instance, general practitioners in the United Kingdom receive capitation

payments and a salary payment as well as fee-for-service payments to encourage the provision of some services, such as maternity care, vaccination and Pap tests.[32]

NACA recommends that:

Provincial/territorial governments adopt methods of reimbursing physician services that combine salary or capitation with fee-for-service to encourage the provision of medical care that is both cost-effective and meets individual needs.

"Individual providers have a moral obligation to treat each individual and consider his/her needs in isolation; these needs must then be referred to a collective process to establish priorities . . . .Decision-making about needs and treatments must be broadened so that physicians are not the ultimate deciders."

Health professionals are morally bound to deploy all the available resources necessary to meet each and every patient's health care needs. They cannot balance their claims against those of other professionals who may also be making legitimate claims on behalf of their patients, nor can they decide which of their equally needy patients should have priority for a particular service. If health professionals were to make decisions to allocate a needed service to one patient but not another, the trust inherent in the professional-patient relationship would be undermined.

Decisions regarding access to services are policy decisions, not clinical decisions, and therefore should be addressed at a level of decision-making that is higher than the micro provider-patient level. The best way of incorporating cost-effectiveness considerations in the access of patients to services is to establish practice guidelines and protocols at the institutional level to orient the decisions of the health professional at the micro level.

NACA recommends that:

Decision-makers at the meso level develop criteria for access to health services by means of clinical guidelines or practice protocols and monitor their application by individual practitioners.

In their efforts to provide care that best meets patients' health needs, health professionals have a responsibility to keep abreast of evidence on the effectiveness of the services they offer, to weigh the relative benefits of a service for a patient and to modify their practice accordingly.[33] By setting priorities for access to services on the basis of patients' capacity to benefit from these services, health professionals act in a morally principled way vis-à-vis each patient. Evidence suggests that only 'reading the literature' and continuing education courses are useful in increasing professionals' awareness of new developments: the wide dissemination of pertinent new knowledge is thus important.[34] Improving knowledge is only the first step in modifying clinical practice, however, and must be supplemented by other methods, such as peer reviews and external practice audits, which provide concrete incentives to change.

NACA recommends that:

The federal government and provincial/territorial governments give high priority to the wide dissemination of knowledge on best clinical practices through the Canadian Institute of Health Information.

Professional associations and health care institutions establish continuing education programs, peer review committees, external practice audits and other methods proven effective both to keep health care practitioners up-to-date with the evidence on the effectiveness of services and to modify their clinical practice accordingly.

4.3 Only the Best Care: The Extent and Limits of Patient Autonomy

> *"Individuals must have the power to decide: risks, possibilities, complications, chances of rehabilitation, procedures and treatments and future care must be explained to them."*

As the person directly affected by health care decisions, the individual patient is entitled to a thorough consideration of all factors that will affect the potential benefits and risks of treatment. The participants at NACA's workshop affirmed that the assessment of benefits and risks of treatment for seniors must take into account supports to seniors' recovery, including the family and support systems available in the community.

As well, the patient has a right to explicit information from the health professionals involved in his/her care regarding the likely benefits and risks of diagnostic and treatment options. Any value judgements made by the professionals in assessing the benefits and risks of recommended care options should be clearly communicated to the patient (e.g., the professionals' assumptions regarding what constitutes an 'acceptable' quality of life or an 'acceptable' duration of life). The representatives of seniors' organizations consulted by NACA were of the firm opinion that the patient is entitled to have as much information as needed and as often as needed to give informed consent to treatment.

Because it is his or her life at stake, the patient's values regarding the quality and duration of life should be known by the health professionals providing care, who in turn, should be guided by these values in determining the plan of care for the patient. As ethicist Jocelyne Saint-Arnaud states:

> It is the patients themselves who know if a treatment is too difficult for them, whether they are prepared to accept resuscitation or chemotherapy that might lead to a longer, but qualitatively diminished life, whether

they could accept a life in a coma, on intravenous feeding or on a respirator for the rest of their life as a quadriplegic.[35]

The participants in NACA's workshop agreed that the quality of life from the patient's perspective should take priority over mere life extension in health care decisions and that individuals must have the ultimate power to decide what happens to them.[36]

NACA recommends that:

All factors influencing a patient's capacity to benefit from health services, including social supports, be taken into consideration in assessing the benefits and risks of treatment options.

Health services be provided only in accordance with a patient's free and informed consent, based on his/her values regarding the quality of life.

In Canada, the patient's right to information and to participation in clinical decision-making is expressed in laws requiring that medical treatment cannot be carried out without the free and informed consent of a mentally-competent patient. For the consent to be free, the individual must be able to choose without undue pressure from health professionals or family who may prefer a certain option for professional, economic or other reasons. Nor should the individual feel abandoned or rejected by them if his or her choice does not coincide with theirs.

An individual also has the right to revoke consent during the treatment and health professionals should respect this change of mind. The patient's right to refuse treatment or to withdraw consent for treatment already begun has been recognized in a number of cases presented to Canadian courts; for instance, in the Nancy B. v. Hôtel-Dieu case, a Quebec judge decided in favour of withdrawing an irreversibly paralysed young woman from her respirator at her request.[37]

In many provinces, the right of competent persons to free and informed consent has been or is in the process of becoming extended to situations where the person is no longer competent, through a living will or advance directive or appointment of a power-of-attorney for personal care.[38] These instruments of patient self-determination in decision-making are usually invoked to protect incompetent patients against the use of extraordinary technologies that may extend life, but compromise the quality of life.

By limiting the use of undesired high-technology life-extension, it is probable that measures such as living wills and advance directives would reduce health care costs to some extent. This economic outcome is, however, secondary in importance to respect for patient self-determination and quality of life considerations. If economic motives were to figure prominently in decisions to encourage patients to use advance health directives, and if there are no means of monitoring attorneys for personal care, these tools of patient autonomy could become subverted into a means of denying health care to individuals with extreme or chronic health needs.

NACA recommends that:

Measures that enhance an individual's capacity to make self-determined decisions regarding health care be legally recognized and widely implemented.

Ethics committees monitor the use of advance directives, living wills and power of attorney for personal care to ensure that their purpose is not subverted to deny legitimate treatment to individuals in need of care.

In some instances, patients and/or their families may demand costly and intensive treatments, perhaps as a 'last resort' in desperate cases; for instance, a patient may request a costly new drug to treat an advanced case of cancer. If the best available evidence suggests that the benefits of such treatment are only marginal, then

the patient has a weak claim to access limited health resources which could be more effectively applied to meeting the legitimate needs of others. Health professionals are morally justified in denying these individual requests, although the denial of access to treatment may undermine the bond of trust between the patient and the treating professional. To maintain the bond of trust between the treating professional and the patient while assuring that the most objective and fairest decisions are made, it may be advisable for such decisions to be made at the institutional level by a committee composed of health professionals and ethicists.

NACA recommends that:

Individual and family requests for access to health services deemed by the treating professional(s) to yield only marginal benefits be considered by independent committees of professionals and ethicists who would evaluate the request based on evidence of the potential benefits in relation to the potential costs.

5. IMPLEMENTING PROCESS VALUES IN DETERMINING HEALTH CARE PRIORITIES

The determination of priorities for Canada's health system is a complex process, involving substantive values that may be either mutually reinforcing or conflicting or that may be applicable at one level of decision-making but not another. Although ethical principles can be clarified at each level of decision-making, the choice of values that will prevail must be made in an explicit, accountable process between decision-makers and stakeholders. During NACA's consultation with national seniors' organizations, several problems with the process of decision-making were raised. These include: 1) a lack of full co-operation between the provincial/territorial and federal governments; 2) 'turf wars' for resources between hospitals and community health services, health services within an institution or among groups of health

professions; and 3) a lack of clear and complete communication and accountability in the relationship between health care professionals and individual patients. To this list, health economists Greg Stoddart and Morris Barer add the general lack of information conveyed to the public. These authors state:

> To date, the job of informing the public done by all parties-including providers, governments, funding agencies, educators and researchers-has been somewhere between nonexistent and 'clearly inadequate'. The information that the public might like to have is . lacking, the mechanisms for transmitting the information are underdeveloped or absent, and the established processes for soliciting the views of the public and using the information in short-term and long-term allocative decision-making are either nonexistent or crude or sporadic.[39]

Throughout this report, NACA has made several recommendations designed to improve the process of health decision-making at the macro, meso and micro levels. NACA is pleased with the recent establishment of the Canadian Institute for Health Information (CIHI) as a means to assemble, synthesize and effectively disseminate knowledge about health and health care. NACA also welcomes the creation of the National Forum on Health as a vehicle for informing the Canadian public and involving it in a meaningful way in making macro-allocation decisions in health care. The Council hopes that the Forum will become a model for participative decision-making at both the macro and meso levels.

While the dissemination of explicit information and the establishment of mechanisms for full and effective stakeholder participation lies with those who ultimately allocate resources--politicians, bureaucrats, trustees and health professionals--the public, collectively and individually, is responsible for demanding information, reflecting on it and becoming involved in the decisions.

NACA's final recommendation is that:

All Canadians demand full and clear information from federal, provincial/territorial and local health authorities on health issues that affect them and their communities and actively participate in the consultations that lead to decisions about health priorities.

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7) Yeo, M., op. cit.

8) Yeo's (ibid.) outline of the relevant ethical criteria concurs with those discussed by other ethicists, including the following:

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21) Since the late 1980s a number of health technology assessment centres and health services

research centres have been established. These include the Canadian Coordinating Office for Health Technology Assessment, the Conseil d'évaluation des technologies de la Santé in Quebec, the Centre for Health Services and Policy Research at the University of British Columbia and the Institute for Clinical Evaluation Studies at the University of Toronto.

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26) Quebec has had a regionalized health care system for several years, with local community service centres (CLSCS) providing community-based health and social services. However, the Quebec Auditor-General has recently criticized the absence of uniform standards of home care in CLSCs across the province.

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32) Soderstrom, L., op. cit.

33) Cuyler, A.J. (op. cit.) advises that "[the doctor's] judgment needs constantly to be exercised by questions like: is the health benefit I predict from this course of action more or less than that from an alternative? Is the benefit worth the expected cost? How much do I actually know about the benefit and how reliable is my diagnosis and prognosis? . . .Am I on top of the available evidence on effectiveness in the literature?"

34) Feeny, D., op. cit.

35) Saint-Arnaud, J. Autonomy, self-determination and the decision-making process concerning end-of-life treatment. In *Writings in Gerontology*, No. 13: Ethics and Aging. Ottawa: National Advisory Council on Aging, 1993.

36) At the present time, NACA is monitoring the hearings of the Special Senate Committee on Euthanasia and Assisted Suicide. Sometime in 1995, the extent to which an individual can decide how and when he or she will die will be determined by an open vote in the House of Commons.

37) Saint-Arnaud, J., op. cit.

38) Currently, advance directives, a mandate or a power-of-attorney for personal care is legally recognized in Nova Scotia,.Quebec, Ontario and Manitoba.

39) Stoddart, G.L. and M.L. Barer, op. cit.

POSITION PAPERS
OF THE
NATIONAL ADVISORY COUNCIL ON AGING

7. The NACA Position on the Goods and Services Tax, February 1990.

8. The NACA Position on Community Services in Health Care for Seniors, February 1990.

9. The NACA Position on Informal Caregiving: Support and Enhancement, September 1990.

10. The NACA Position on Lifelong Learning, October 1990.

11. The NACA Position on Gerontology Education, December 1991.

12. The NACA Position on Managing an Aging Labour Force, February 1992.

13. The NACA Position on Canada's Oldest Seniors: Maintaining the Quality of their Lives, January 1993.

14. The NACA Position on the Image of Aging, February 1993.

15. The NACA Position on Women's Life-Course Events, September 1993.

16. The NACA Position on Community Services in Health Care for Seniors: Progress and Challenges, March 1995.

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