This paper is one of a series of nine public discussion documents designed to help Canadians make informed decisions about the future of Canada’s healthcare system. Each of these research-based papers explores three potential courses of action to address key healthcare challenges. Canada may choose to pursue some, none, or all of these courses of action; in addition, many other options are available but not described here. These research highlights were prepared for the Commission on the Future of Health Care in Canada, by the Canadian Health Services Research Foundation.
Thank you for your interest in shaping the future of Canada’s healthcare system.

This discussion document and survey on Homecare is one of a series of nine such documents the Commission on the Future of Health Care in Canada has developed in partnership with the Canadian Health Services Research Foundation. They were designed to enable Canadians to be better informed about some of the key challenges confronting their health care system and to express their preferences on proposed solutions. We have worked hard to summarize relevant, factual information and to make it as balanced and accessible as possible.

Each of our nine documents follows an identical format. We begin by briefly summarizing a particular health issue. Next, we identify three possible courses of action to address the issue and their respective pros and cons. Last, we ask you to complete a brief survey relating to the courses of action.

To make it easier to provide us with your responses, the survey questions are included on the final pages of this document. Please detach and forward these pages to us by fax at: (613) 992-3782, or by mail at:

Commission on the Future of Health Care in Canada
81 Metcalfe, Suite 800
Ottawa, Ontario
Canada K1P 6K7

You can also complete the survey on-line through our interactive website at: www.healthcarecommission.ca.

There are no “right” or “wrong” answers, and the results are intended to be informational only. They are designed to illustrate how each person’s response fits within the context of others who have responded, not to have scientific validity in and of themselves. The survey results are only one of many ways the Commission is studying and analyzing this issue. To order other titles in this series, please write to us at the address above, or call 1-800-793-6161. Other titles include:

- Pharmacare in Canada
- Access to healthcare in Canada
- Sustainability of Canada’s healthcare system
- Consumer choice in Canada’s healthcare system
- The Canada Health Act
- Globalization and Canada’s healthcare system
- Human resources in Canada’s healthcare system
- Medically necessary care: what is it, and who decides?

We are grateful for your contribution to shaping Canada’s healthcare system and hope that this document will be as informative to you, as we know your survey responses will be valuable to us.

Sincerely,

Roy Romanow
Homecare in Canada

Homecare is a fact of life in Canada. Hundreds of thousands of people across the country are receiving care at home that not long ago would only have been given in institutions. But homecare has grown piecemeal. Its development has been spurred by budget cuts that pressured hospital managers to get patients out the door, medical breakthroughs that have made it possible to deliver many types of care outside of institutional walls, and values that lead families to keep the frail, the chronically ill and even the dying at home rather than send them away to an institution.

Like the rest of the healthcare system, however, homecare is in upheaval. Demand for services increases daily, far outpacing increases in funding. Lack of co-ordination and system-wide planning often means patients are sent home even if there are not sufficient services in the community to care for them. And society has done little to support family, friends and neighbours — the unpaid caregivers — who put in endless hours looking after people who once would have been the responsibility of the system.

But what can we do to deal with the problems of homecare? Should we throw out all the existing homecare systems and start again? Or should we try to build on what we have, perhaps adding funding and changing policies to improve it?

Before we can address homecare issues, we should establish what we’re talking about. Homecare is much more than medical professionals going to peoples’ houses to give treatments. Instead, it’s an incredibly diverse picture that sees people of all ages getting services that range from taking blood pressure, giving medication and changing dressings to providing personal care, homemaking and time off for family members and friends who give care.

Generally, homecare can be broken down into three types: “maintenance homecare” that helps care receivers who have a chronic illness or disability stay in their home at a stable level of health; “long-term homecare” which substitutes for care in an institution such as a nursing home; and “acute homecare”, which usually substitutes for care in a hospital, and is given to people who require or are recovering from significant medical treatment.

The growth of homecare in Canada

In the last 25 years, homecare has grown like Jack’s beanstalk. Government spending on homecare is growing much faster than other healthcare spending — between 1975 and 1992, it grew twice as fast as total health spending (19.9 percent vs 10.8 percent). Since 1992, it has grown at three times the pace. That trend is expected to continue. Predictions are homecare expenditures will jump almost 80 percent between 1999 and 2026. Despite its growth, homecare still accounts for only one out of every twenty dollars governments spend on health.

Does homecare save money? Is it cost-effective? Several U.S. studies have found homecare is not cost-effective, but their system is not really comparable to ours. Some Canadian researchers have produced similar findings, but more recent work concludes that homecare does save money, at least in some circumstances. The jury is still out on the cost-effectiveness of maintenance homecare, but we know acute and long-term homecare can save money if homecare means a bed in an institution is closed.
It is important to remember, however that cost-effectiveness shouldn’t be limited to how much money the government saves. It should also be about the money saved by, or costs to, care receivers, or their unpaid caregivers.

There are many arguments against homecare. Some say apartments and houses are not well-equipped for providing care and may present safety issues for both caregivers and care receivers. Others think homecare programs assign to governments a task traditionally done by families and the community. Some argue it still should be a family’s and community’s task; others say that idea is outdated because of all the changes to family structures over the last 20 years. There are fears that homecare is bad for the health of its unpaid caregivers — research shows they report worse health, and use prescription drugs for depression, anxiety and insomnia two to three times more than the rest of the population. But that might be caused by the stress of watching a loved one suffer, among other things.

Focusing on the negatives, however, can obscure other important issues — like the satisfaction that unpaid caregivers get from helping those who need them or the positive effects that being at home may have on health. So the assumption that homecare is always a burden is not true. One Canadian study notes that acute homecare made no difference to caregivers’ sense of burden or the amount of time they spend on caregiving.

This paper focuses on three of the many potential courses of action for Canada. They are:

I. Government should fund a national homecare program;

II. Government should provide support, including tax breaks, for unpaid caregivers; and

III. Government should make sure that when services that are publicly funded in an institution are provided in the home, they continue to be publicly funded.
A legion of homecare users and providers, advocacy groups, politicians and researchers argue that Canada needs a national homecare program. They claim that the absence of a national program has left gaps in coverage and allowed barriers to develop that keep some Canadians from getting the care they need. Their basic argument is the same: the patchwork approach means Canadians get homecare based more on where they live and what they can pay than on what they need.

Course of action: The government should fund a national homecare program

A national homecare program could be set up in one of three ways. First, homecare could be made a part of medicare. If the Canada Health Act were rewritten to specifically include homecare, then a national program would be subject to the same principles as medicare and the provinces would have to reform their policies to ensure universality, accessibility, portability, and comprehensiveness. There would be no extra billing or user fees and the principles of medicare would be guaranteed.

Some people would prefer to see a separate program, outside of medicare. Payment for care (perhaps through deductibles or co-payments) could be allowed. Such a program could be privately or publicly run. This approach would allow the development of more specific national standards. Creating something new outside the Canada Health Act would not mean that some of the principles in the Act couldn’t also be applied to the new legislation. In fact, borrowing parts of the Act would be indispensable in addressing inequality and unmet needs. And to maximize the cost-effectiveness, principles like a single point of entry into homecare, and common standards for assessment of needs, would have to be part of the program.

The third option would be to leave homecare as the piecemeal set of services it is now, but with a commitment from government to fill in the gaps. Those who don’t get homecare or all the services they need will be better served, and it could be subsidized where necessary, perhaps through workplace insurance programs. Low-income Canadians could be guaranteed homecare.

The cost of any of these options would likely be split between the federal and provincial governments, but where the money would come from is another issue. There are those who argue a well-run system would generate enough savings to pay for itself. Others feel millions of dollars of new revenue will have to be found, perhaps from higher taxes or user fees, or even some form of private insurance.

Where to set limits would probably be the biggest barrier to successfully negotiating a national homecare program. Some might argue that homecare should include programs to prevent disease, encourage exercise and even provide appropriate housing or improve public transportation — since all of that, ultimately, helps to make and keep people well.

Arguments for

**Canadians want it.** A 1998 poll by the Canada Health Monitor found that 84 percent of Canadians want a national homecare program. Other polls show similar findings.

**A national program could ensure comparable access and service.** Many of Canada’s homecare needs are not being met. Canadians who live in rural areas or have low incomes may not get equal access under an “open market” approach. Similarly, different provinces offer different access to care. A national program could also ensure that homecare is portable across provinces, without a waiting period when Canadians enter a new province.
Administrative costs could be reduced. Currently, payment for a single recipient’s homecare may come from several sources — provincial and federal governments, insurance companies and their own pockets. A single national program would eliminate the need for multiple administrations and be less expensive to run.

Arguments against

Research results on the effectiveness of homecare are mixed. Since we don’t know for sure what types of homecare are effective, it may be too soon to draw up a plan for a national program.

Canada’s homecare compares well to other members of the Organization for Economic Cooperation and Development. Seventeen percent of elderly persons receive formal homecare services in Canada compared to 16 percent in the U.S., 11.7 percent in Australia, 5.5 percent in the U.K., and 5 percent in Japan.

It could be expensive. Some experts believe it could cost millions or even billions to implement homecare nationally.

Getting agreement will be a long, tough slog. Identifying the boundaries around what is (and isn’t) homecare is difficult, and it is tough to stop those boundaries from creeping outward (or shrinking). Also, homecare policies have been developed independently in each province for 20 to 25 years and recent efforts at healthcare reform have shown how difficult it can be to reach a consensus on a national policy.

Survey questions

Please refer to page 11 for the survey questions for this section.
Some people argue that what’s needed is more support for the family and friends who help to look after people at home. Without the care of these “unpaid caregivers”, homecare wouldn’t work. Luckily, people are quick to do their bit: it’s estimated that up to 90 percent of homecare services are provided free of charge by friends and relatives.

But there are costs associated with unpaid care. Often, the unpaid caregivers are there because other options aren’t available — because there is no government program (or they’re full), or the homecare recipient can’t afford to pay outright or even to cover user fees, or he or she has been judged ineligible for government support. Unpaid caregivers may spend their own money on equipment for the recipient. They often spend more on heating and food, or have to hire someone to take care of children and housework because they’re caring for someone at home. At the same time, unpaid caregivers may lose money and diminish their pensions and savings by being away from work.

**What Canada is doing now for unpaid caregivers**

Direct support for caregivers is uncommon — most government support is aimed at the people who need the care, not those who look after them. However, most provinces offer self-managed care programs, which give individuals the option to pay their caregivers. Since 1998, the federal government provides the Caregiver Tax Credit, which gives some live-in caregivers looking after a dependent relative over 65 up to $560 off their federal income tax. Quebec provides up to $600 annually for caregivers to purchase respite care.

**Course of action: Government should provide support, including tax breaks, for unpaid caregivers.**

In 1995, the estimated value of the work being done by unpaid caregivers for just the elderly was pegged at up to $5.7 billion per year. For all homecare today, it’s obviously much higher. In 1996, 2.8 million Canadians — 12 percent of the population — reported providing unpaid assistance to someone with long-term health problems. All of those people stand to benefit from improvements to support programs.

There are two ways to offer support to unpaid caregivers. The first is direct support — cash, service vouchers, or some kind of care allowance — so that caregivers (or the recipients) won’t have to pay for care. Some can’t afford this, even if they’re reimbursed later — they just don’t have the extra money. Indirect support doesn’t necessarily ease the burden of caregiving upfront, though things like pension schemes, registered homecare savings plans, or tax breaks for unpaid caregivers can ease the long-term financial burden of caring for someone at home.

There can also be more community programs to ease the demands of caregiving, such as daycare centres for people otherwise cared for at home, more home visits by professionals, and “respite care” programs, which let caregivers take a break. Unpaid caregivers’ workplaces could help with better policies on family leave, and provisions in the Canada Pension Plan could allow Canadians to give homecare temporarily without hurting their pension status.

**Arguments for**

Unpaid caregiving happens whether support is given or not, therefore we need to support it. Any support programs the government puts in place would be a symbolic recognition of the value society puts on unpaid caregivers’ work and would hopefully help alleviate some of the caregivers’ load. And those who receive support provide care longer.
Lack of unpaid caregiver support tends to discriminate against women. It is well-known that women make up the majority of caregivers (and are usually the primary caregiver, even if a man is also giving care.)

Lack of support for unpaid caregivers is an incentive to institutionalize. Case managers may be tempted to keep a care recipient in an institution if they know they may be cared for by an elderly spouse at home, or someone who is short of cash or juggling child-rearing and work.

Support for unpaid caregivers can help them continue to participate in the workforce. Unpaid caregivers are known to have increased absenteeism from work, lateness, and difficulty keeping to a regular shift. In Canada, 32 percent of people with conflicts between their work and home life turned down or chose not to apply for promotions and transfers and considered quitting — or actually quit — their jobs. Families are often caught between paying for care in an institution like a nursing home, paying for homecare, or losing income because giving care at home is competing with their job.

Helping unpaid caregivers and care receivers get more control over who is hired to care for them increases their feelings of satisfaction. In Ontario, disabled people receiving homecare who were given cash to hire care providers reported feeling an increase in autonomy, reduced vulnerability, greater independence, stronger self-esteem, more fulfilling personal relationships and more social and employment participation.

Arguments against

Homecare happens whether support is given or not. Some see it both as a duty and a privilege to take care of relatives.

The easiest support to organize — extra cash — won’t always help. Giving money to caregivers doesn’t help anyone unless there are services available to purchase with those funds. Often, there are not.

Tax breaks benefit the wealthy more than they do the poor. One U.S. study found a disproportionate number of higher-income households benefit from homecare tax-incentive programs. The U.S. federal tax credit didn’t help low-income families because they didn’t earn or spend enough money to benefit from a tax break.

Giving tax breaks gets complicated. Tax incentive programs are limited by the complexity of figuring out who is eligible for the tax break and, to a lesser degree, what their work is worth.

Individuals may not be qualified to choose homecare services. Providing recipients or their caregivers with money or vouchers may lead them to buy substandard care or force them into choices they might not be qualified to make.

Survey questions

Please refer to pages 11 and 12 for the survey questions for this section.
Expanding Funding for Acute Homecare

In the hospital, patients don’t have to worry about the cost of the drugs, services and equipment they need. But when it’s time to go home, they suddenly have to pay for expenses that were covered when they were in the hospital, including medication, bandages and dressings, even wheelchairs.

In most parts of Canada, medical and nursing services are usually delivered free to people at home, although the time professionals spend with care receivers is quite restricted. Care receivers often have to pay fees, however, for personal care and homemaking services, and there may be direct charges or partial payments based on income, for prescription drugs, medical supplies, or adaptive equipment.

Course of action: Government should make sure that when services that are publicly funded in an institution are provided in the home, they continue to be publicly funded.

An expanded acute homecare system would ensure a minimum level of the services patients receive in hospital. Medications, other treatments such as physiotherapy, overall monitoring and assistance for tasks like using the bathroom or eating would be supplied and paid for from the public purse.

When a care receiver is in the hospital, non-medical services like clean linen and help with baths are part of the service. Should they also be included in homecare funding? And to what extent? Hospitals are supposed to be clean and tidy, but if you normally live in a messy house, should the public purse pay to clean it when you’re sick? Should a homecare client pay for their own medications, which they don’t have to do in hospital?

ARGUMENTS FOR

When drugs, dressings and care devices are funded by medicare in the hospital but not at home, there is an incentive to opt for hospital care. Providers will want to keep patients in hospital because they know they can’t pay for the care they need at home.

Extra costs outside hospital can create barriers to care. The working poor and the poorest seniors suffer when there are extra charges. The extra costs can lead to these people simply not buying the care they need, which in turn can increase the overall cost of healthcare because when they finally do get care, their needs are more acute.

If care moved from institutions to the home were covered by the Canada Health Act, it would be protected and equal access guaranteed. There still isn’t much research on exactly how much out-of-pocket costs are for services that are covered in an institution, but not at home. We know, however, that any extra cost is too much for some.

If the gap between what is covered in an institution and what is paid out-of-pocket at home increases, it may well mean more unintended passive privatization. Private funding to homecare is growing rapidly, although not as fast as government spending. Across the whole health system, out-of-pocket payments and private insurance grew from 23.6 percent of all health spending to 30.4 percent in 1999. This is a much broader issue that requires extensive discussion, and relates to the erosion of a system that Canadians take pride in. More on privatization is discussed in another part of this discussion series that addresses whether the healthcare system is financially sustainable.
Arguments Against

It’s too confusing to pay for acute homecare based on what’s covered in hospital. The nature of healthcare is changing; many procedures simply don’t require hospitalization anymore. At what point do you draw the line? Should we instead just focus on what is considered “medically necessary”?

The out-of-pocket costs of acute homecare aren’t very large. Perhaps funding should be concentrated elsewhere, where the need for support is greater. In 1998, a study of 800 Saskatchewan patients found that patients who received post-acute care were able to be cared for at home with family support and homecare services. The health of the care receivers didn’t change with early discharge, and the burden on family caregivers did not increase, except for out-of-pocket costs which went up an average of $11. Instead of expanding acute homecare, what might be funded instead is better management of who gets sent home from hospital, so that people who can’t afford any out-of-pocket costs from acute homecare won’t have to pay for it.

Survey Questions

Please refer to page 12 for the survey questions for this section.
Acknowledgements

This document was produced by the Canadian Health Services Research Foundation, in partnership with the Commission on the Future of Health Care in Canada. The topics and courses of action reflect key issues raised frequently in the Commission’s consultations to date, for which the Foundation was able to find relevant research evidence to help inform the debate.

This document has been reviewed by the following experts for accuracy and fairness, but final responsibility lies with the Canadian Health Services Research Foundation:

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A complete bibliography of the research used to prepare these documents can be found at www.healthcarecommission.ca.

Survey Instructions

Please detach the following page and forward to us by fax at:  
(613) 992-3782

Or by mail at:  
Commission on the Future of Health Care in Canada  
81 Metcalfe, Suite 800  
Ottawa, Ontario  
Canada K1P 6K7

For information:  
Call toll free at 1-800-793-6161  
www.healthcarecommission.ca

Thank you
Survey Questions

For each of the following questions, please indicate your opinion by selecting the appropriate box.

### A National Homecare Program

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<thead>
<tr>
<th>Question</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
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<tbody>
<tr>
<td>1. Creating a national homecare program will improve healthcare in Canada.</td>
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<td>2. Government should increase healthcare spending in order to create a national homecare program.</td>
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<td>3. A national homecare program should only cover expenses when homecare is cheaper than institutional care.</td>
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<td>4. Do you believe that a national homecare program should only cover medically necessary services or do you believe that it should also cover social support services — like meal preparation and housecleaning — where providing these services will probably reduce hospital use?</td>
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<td>5. Please rank the following options for a national homecare program in order of preference, with 1 being your most favoured option and 4 being your least favoured option.</td>
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### Supporting Unpaid Caregivers

1. Which of the following is closest to your own point of view on who should bear the responsibility for homecare?

   Caring for injured, disabled, or older people in the home is the responsibility of their family and friends, not the government.

   OR

   Government should provide as much formal homecare as needed so that we don’t rely on family and friends to provide care to injured, disabled or older people in the home.
2. Providing more support to unpaid caregivers will improve healthcare in Canada.

3. Government should increase healthcare spending in order to support unpaid caregivers through tax breaks, respite care, day hospitals and other means.

4. Please rank the following approaches for supporting caregivers in order of preference, with 1 being your most preferred and 3 being your least preferred.

- We should support unpaid caregivers directly, with cash service vouchers and car allowances. 1
- We should support unpaid caregivers indirectly, with tax breaks. 1
- We should focus on programs which give unpaid caregivers a break, such as respite care, increased professional caregiver visits and geriatric day hospital programs. 1

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**EXPANDING FUNDING FOR ACUTE HOMECARE**

1. Publicly funding all services in the home that are publicly funded when provided in an institution will improve healthcare in Canada.

2. Government should increase healthcare spending in order to fund all services in the home that are publicly funded when provided in an institution.

3. If government were to pay for certain products and services provided in the home (which paid for when provided in the hospital), which products and services should be covered?

   - Drugs
   - Bandages and dressings for wounds
   - Medical devices
   - Therapies like physiotherapy
   - Equipment or home modification needed to stay at home
   - Non-medical monitoring and assistance for things like eating, bathing, using the bathroom

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**ANALYSIS INFORMATION**

Please complete the following information for analysis purposes. Thank you.

- Gender: □ Male □ Female
- Age: □ under 18 □ 19-29 □ 30-49 □ 50-65 □ over 65
- Province or Territory in which you reside: ________________________
Your annual household income from all sources before taxes is: (Optional)
Choose one:
- Less than $20000
- $20000 to $39999
- $40000 to $59000
- $60000 to $79000
- $80000 to $99000
- More than $100K

The highest level of schooling you have completed is: (Optional)
Choose one:
- Elementary School or less
- Secondary School
- Community College/CEGEP/Trade School
- Prof./Trade Certification
- Bachelor Degree
- Graduate Degree

Are you a healthcare professional? (Optional)
- Yes
- No

Approximately how many times in the last year have you personally used the healthcare system? (eg. seen a doctor or specialist, spent time in the hospital, received care in a hospital emergency room, etc.) (Optional)
Choose one:
- 0-3
- 4-6
- 7-9
- More than 10