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Canadians' Experiences with Chronic Illness Care in 2007

A DATA SUPPLEMENT TO

Why Health Care Renewal Matters: Learning from Canadians
with Chronic Health Conditions



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HEALTH COUNCIL OF CANADA

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Why Health Care Renewal Matters: Learning from Canadians
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EXECUTIVE SUMMARY

Chronic conditions afflict nearly one in three Canadians, or over nine million people, and rates are expected to increase due to population aging and rising trends in risk factors (e.g. obesity). These conditions represent a significant health and economic challenge, as they are associated with co-morbidity and are key drivers of quality of life, health care use, and health care costs.¹

Health care delivery must be tailored to serve the ongoing and complex needs of patients with chronic conditions to improve health and reduce the strain on the health care system. High-quality chronic illness care requires that patients have timely access to health care providers, and that care is responsive to their needs and preferences, is integrated across multiple care providers and sites, and is comprehensive so that it addresses the gamut of services, from health promotion and disease prevention to treatment. Additionally, effective chronic illness care involves the inclusion of patients in making important care decisions and gives them the knowledge and tools to effectively manage their own condition.

This is a data supplement to the second report in a series by the Health Council of Canada on health status and outcomes for Canadian adults. The data reflect the responses of adult Canadians to survey questions about their experiences with access to and use of primary health care and chronic illness care. Comparisons have been made based on the responses of two groups within the survey population: those with one or more of seven high-impact and/or high-prevalence chronic health conditions and those without any of these select chronic conditions.

More context and commentary on chronic illness care in Canada can be found in the report *Why Health Care Renewal Matters: Learning from Canadians with Chronic Health Conditions*, available at www.healthcouncilcanada.ca.

Key findings

In general, survey participants gave good ratings to interactions among health care professionals and to their responsiveness, communication, continuity, and coordination of care. Participants expressed confidence in their ability to manage their own care. They gave lower ratings to accessibility of care, levels of follow-up, and the comprehensiveness of health promotion and disease prevention services.

OVERALL HEALTH

- › 75% of adults with chronic conditions rate their health as “excellent,” “very good,” or “good”— a much smaller proportion than that of adults with no chronic conditions who responded likewise (96%).

USE OF AND ACCESS TO PRIMARY HEALTH CARE

- › The majority of adults with chronic conditions (93%) report having a regular medical doctor.
- › 98% of adults with chronic conditions report having a regular medical doctor or place to go if they are sick or need advice about their health.
- › Over half of adults with chronic conditions who have a regular medical doctor or place of care (59%) have been affiliated with this primary care provider* for more than seven years.
- › Many adults with chronic conditions report that they required routine or ongoing care (55%), immediate care for a minor health problem (31%), or specialist care for diagnosis or consultation (51%), or that they visited an emergency department in the past 12 months (33%).
- › Few adults with chronic conditions (10%) report that there was a time in the previous year when they needed health care but didn’t get it.
- › Adults with chronic conditions report having difficulty accessing routine or ongoing care (20%), immediate care (21%), or specialist care (24%); waiting too long for an appointment was the top reason respondents cited when asked about their difficulty accessing routine or specialist care.
- › One-third of adults with chronic conditions (33%) who visited an emergency department in the last 12 months report that their last visit was for a condition that could have been treated by their primary care provider if he/she had been available.

* In this report, we use the term *primary care provider* to refer to a regular medical doctor or regular place of care.

HEALTH CARE MANAGEMENT

- › One-third of adults with chronic conditions (33%) who have a regular medical doctor or place of care report that there is a nurse working with their primary care provider who is regularly involved in their care; fewer (18%) report that other health care providers, such as dietitians and nutritionists, work in the same office as their primary care provider.
- › The majority of adults with chronic conditions (89%) “strongly agree” or “agree” that the health professionals who serve them at their regular place of care work well together.
- › Again, the majority of Canadian adults with chronic conditions (89%) who have a regular medical doctor or place of care “strongly agree” or “agree” that the health care professionals who serve them work well with other professionals they consult elsewhere, such as pharmacists and physiotherapists.

RESPONSIVENESS, COMPREHENSIVENESS, COMMUNICATION, AND COORDINATION OF PRIMARY HEALTH CARE

- › Most adults with chronic conditions report that their primary care providers always find out what their concerns are (60%) and take them very seriously (69%).
- › Too few adults with chronic conditions (37%) report that they always get the help they need to make changes in their habits or lifestyle that would improve their health or prevent illness.
- › Most adults with chronic conditions report that when a physical exam (63%) or tests (68%) were conducted, the results were always clearly explained.
- › Over half of adults with chronic conditions (58%) report that their medical doctors and pharmacists always explained the side effects of medications that were prescribed to them, but almost one-third (31%) report that this “rarely / never” occurred for all medications they were using.
- › Most adults with chronic conditions (78%) report that they did not receive conflicting information from different health care professionals.

WHOLE PERSON CARE AND SELF-MANAGEMENT

- › 45% of adults with chronic conditions were “almost always/most of the time” asked how their chronic condition affects their life.
- › 44% of adults with chronic conditions were shown that what they did to take care of themselves had influenced their chronic condition.
- › 44% of adults with chronic conditions were “almost always/most of the time” helped to make a treatment plan that they could carry out in their daily life, but 29% had no treatment plan at all.
- › Most adults with chronic conditions (70%) were “generally not/almost never” encouraged to attend programs in the community that could improve their health.
- › 62% of adults with chronic conditions “generally not/almost never” received follow-up care after a visit with their doctor to see how things were going.

PATIENT KNOWLEDGE AND CONFIDENCE IN SELF-MANAGEMENT

- › Almost all adults with chronic conditions (97%) “strongly agree” or “agree” that they are responsible for managing their own health.
- › Fully 96% of adults with chronic conditions are confident in knowing when they need to get health care and when they can handle a health problem on their own.
- › 90% of adults with chronic conditions know what each of their prescribed medications does.
- › Most adults with chronic conditions (88%) “strongly agree” or “agree” that they have been able to maintain lifestyle changes for their health.

PERCEIVED QUALITY OF CARE AND CONFIDENCE IN CARE

- › Most adults with chronic conditions (79%) report that the quality of care they have received from their primary care provider has been either “excellent” or “very good.”
- › 32% of adults with chronic conditions report a high level of confidence in being able to get quality and safe care when they need it.
- › Half of adults with chronic conditions report that their confidence in the system is relatively unchanged.

METHODS

About the survey

The Health Council of Canada developed the Canadian Survey of Experiences with Primary Health Care to provide new information about access, use, experiences, and outcomes among the general population as well as adults who have chronic health conditions. Importantly, these survey data offer the only source of pan-Canadian population-based estimates on the topic of experiences with primary health care and chronic illness care.

The survey was created by combining questions previously used in Canada with those used in other countries. In particular, the section of the survey dedicated to assessing the quality of chronic illness care was derived from the Patient Assessment of Chronic Illness Care, which is based on a popular chronic care model.²

This cross-sectional telephone survey was conducted by Statistics Canada in January and February 2007 and administered in either French or English (depending on the preference of the survey participant). A stratified random sample of adults completed the survey (n=2,194). All participants had previously participated in Statistic Canada's Canadian Community Health Survey (CCHS) Cycle 3.1, conducted in 2005.

Adults 18 years or older who live in private households in 10 provinces and three territories were contacted, yielding a response rate of 58%. Results are weighted to be representative of the age and gender distribution of the population. Residents of Indian Reserves and Crown land, full-time members of the Canadian Armed Forces, inmates of institutions, and residents of isolated areas were excluded. No data have been reported that would compromise individual privacy or confidentiality. Instances where small sample sizes require caution in interpreting results have been noted.

Data are based on the responses of adults who reported that they had been diagnosed by a health professional as having one or more of the following select chronic conditions for six months or more: arthritis, cancer, chronic obstructive pulmonary disease (COPD), diabetes, heart disease, high blood pressure, and mood disorders. Hereinafter we refer to these respondents as adults with chronic conditions. We selected these conditions because they have a high prevalence in the population and/or high impact on health care use.³ The number of people reporting that they have COPD may not be fully representative of the population with COPD since our results may not include chronic bronchitis or emphysema and are based on the simple question, "Do you have chronic obstructive pulmonary disease (COPD)?" Mood disorders include depression, bipolar disorder, mania, and dysthymia. Arthritis includes rheumatism.

Limitations of these data

We recognize that respondents may have other chronic conditions not captured in our data and that undiagnosed or unreported conditions could have a substantial impact on health status and use of health care. In addition, the survey relies on respondents' ability to recollect a diagnosis. Finally, we have not included people who were in hospital or other institutions at the time of the survey.

DETAILED RESULTS AND FIGURES

Overall health

- > In 2007, one-third of Canadian adults (33%) report having been diagnosed with a select chronic condition. This prevalence is similar to that measured using Statistics Canada's Canadian Community Health Survey, 2005.⁴
- > Adults with chronic conditions report poorer health status than those with no chronic conditions.

Three-quarters of adults with chronic conditions (75%) rate their health as "excellent," "very good," or "good," which is a much lower proportion than the proportion of adults with no chronic conditions who responded likewise (96%) (Figure 1).

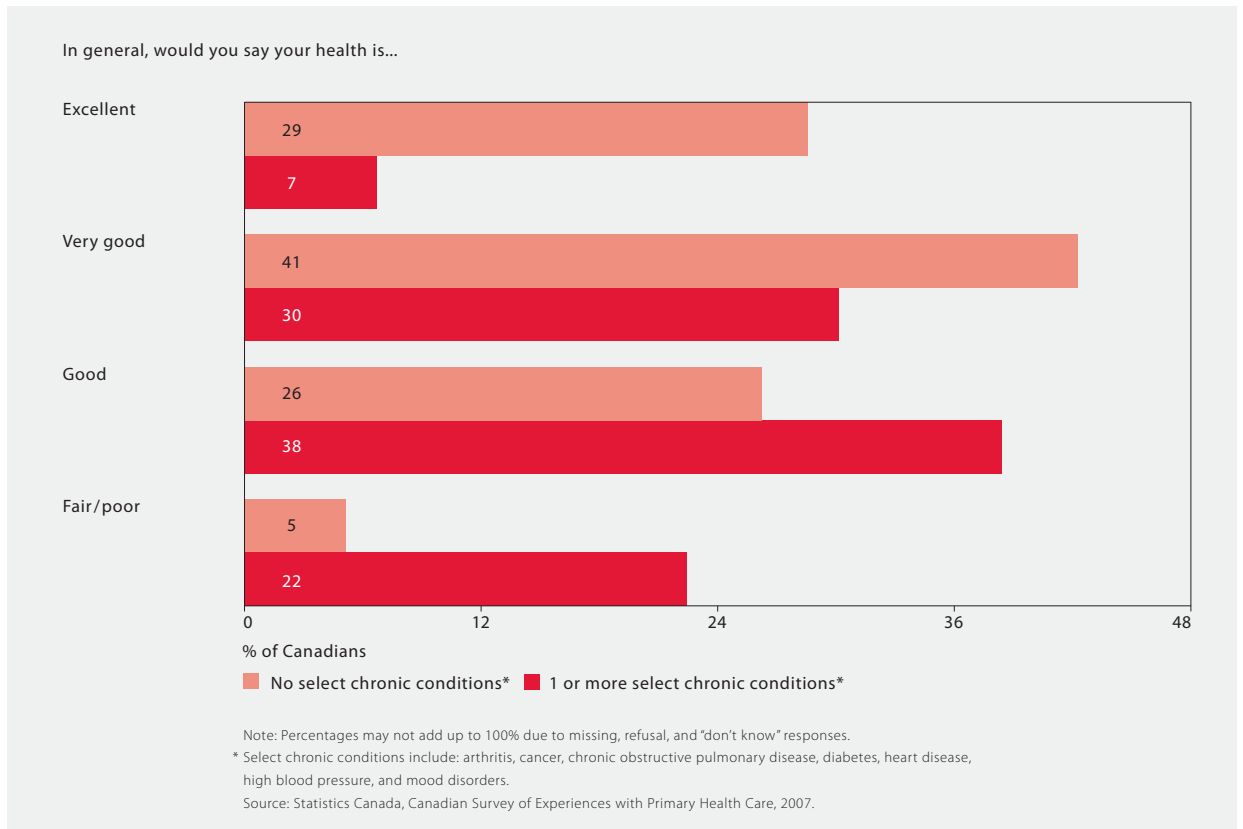
Use of and access to primary health care

- > Most adults with chronic conditions have a regular source of care and have had one for a long time.

The majority of adults with chronic conditions (93%) report having a regular medical doctor, slightly higher than the proportion of adults with no chronic conditions (82%). Among the small group of adults with chronic conditions who do not have a regular medical doctor, most report having a place to go if they are sick or need advice about their health. In total, 98% of adults with chronic conditions have a regular medical doctor or place of care, compared with 95% of those with no chronic conditions.

Over half of adults with chronic conditions who have a regular medical doctor or regular place of care have been affiliated with this provider for more than seven years (59%, compared with 53% of those with no chronic conditions) (Figure 2).

FIGURE 1
Canadians with select chronic health conditions* describe their health



6

In 2007, more than half of adults with chronic conditions required routine or ongoing care (55%), and many required immediate care for a minor health problem such as a fever or sprain (31%). By comparison, only about one-quarter of adults with no chronic conditions report that they required routine or ongoing care (25%) or immediate health care services for a minor health problem (28%). In terms of visits to specialist physicians for a diagnosis or consultation, almost double the number of adults with chronic conditions report having required this type of service in comparison to those with no chronic conditions (51% and 27%, respectively) (Figure 3).

- › Many adults report that they experience difficulty with access to primary health care. The most common reason cited among both groups was waiting too long for an appointment.

Just less than one-quarter of adults with chronic conditions (20-24%) report experiencing difficulties with access to any of the types of care discussed above, while a slightly higher proportion of adults with no chronic conditions (23-32%) report difficulties (Figure 4).

The most common type of difficulty in accessing care cited by people with chronic conditions was waiting too long for an appointment for routine or ongoing care (37%) or specialist care (61%). Among Canadian adults with no chronic conditions, 51% report waiting too long for both routine and specialist care. Few adults in both groups report that there was a time when they needed health care but didn't get it (10% of those with chronic conditions, 9% with no chronic conditions) (data not presented).

FIGURE 2
Length of time with primary care provider

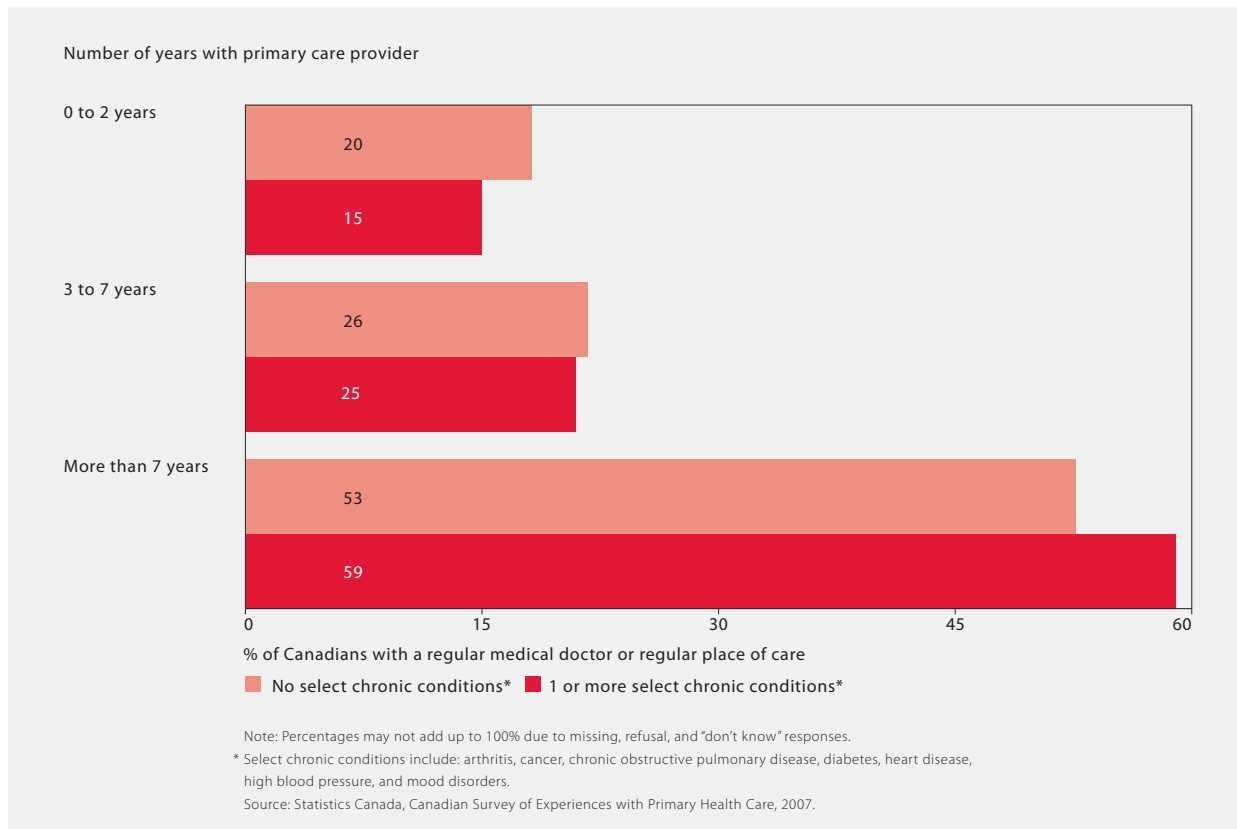


FIGURE 3
Canadians' need for routine, immediate, and specialist care in past 12 months

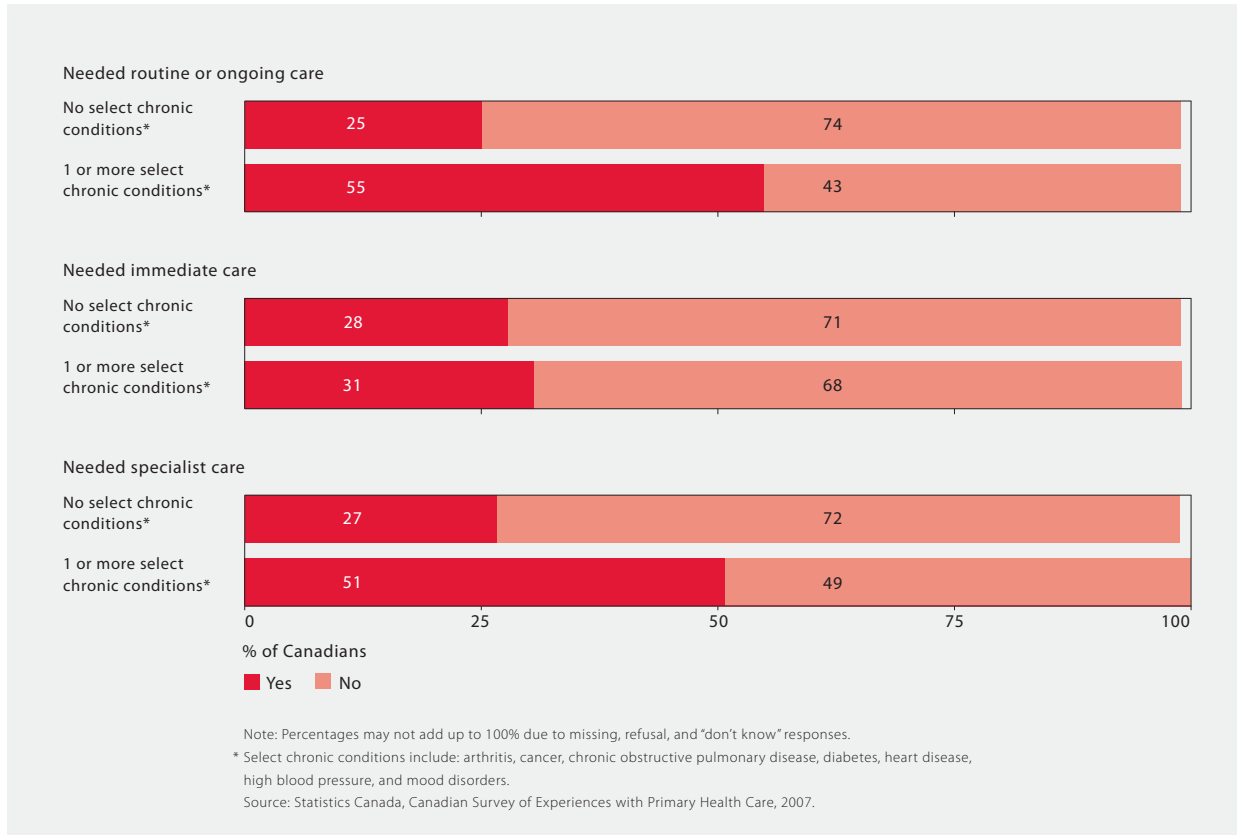
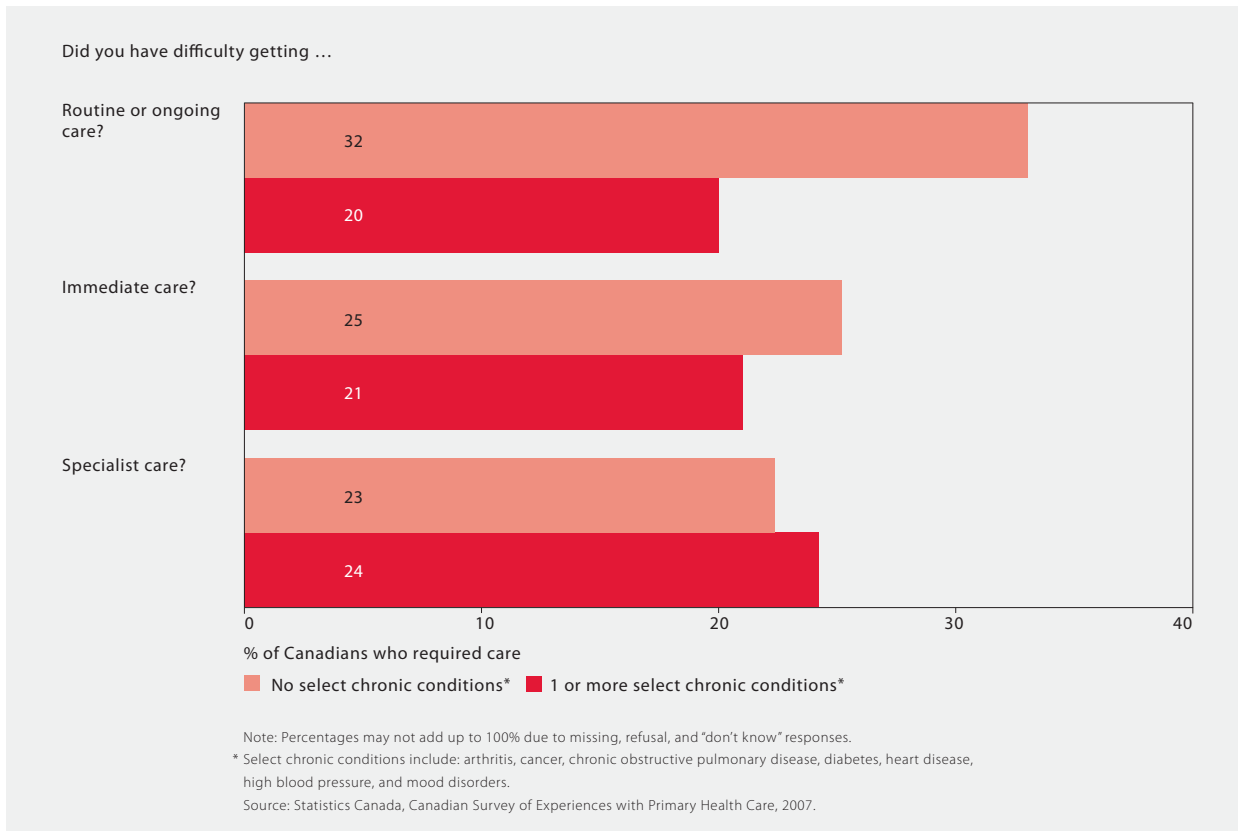


FIGURE 4
About one-quarter of Canadians have difficulty accessing care



- 8 > Too many adults with chronic conditions visit hospital emergency departments unnecessarily.

Of the 33% of adults with chronic conditions who visited a hospital emergency department within the past 12 months, one-third (33%) report that the last time they went, it was for a condition that they believe could have been treated by their primary care provider if he or she had been available; the corresponding share for those without chronic conditions was higher, at 43% (Figure 5).

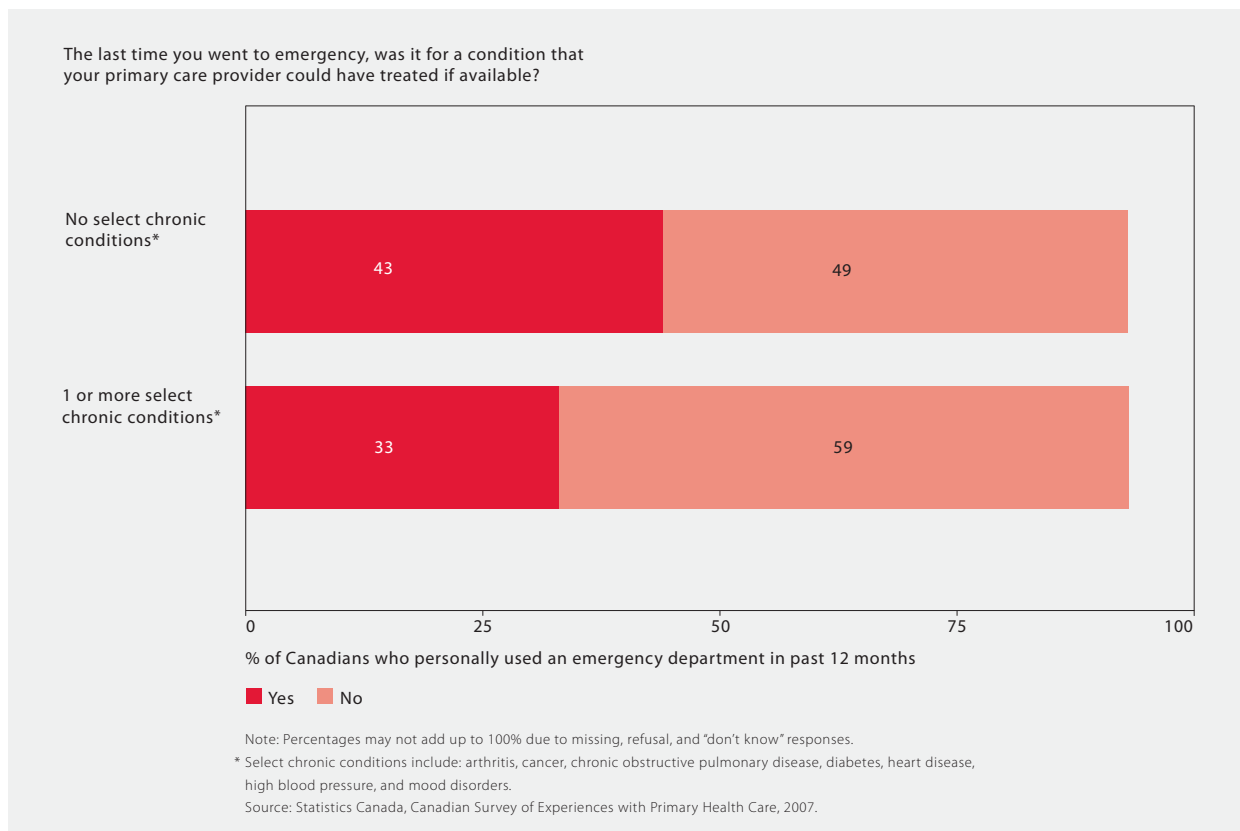
Among adults with chronic conditions who used a hospital emergency department within the past 12 months for immediate care, about one-quarter (24%) report that they waited four or more hours before being treated. Of the 19% with no chronic conditions who sought emergency treatment, roughly an equal proportion (23%) waited the same amount of time.

Health care management

- > Too few primary care providers work in multidisciplinary settings with other health care professionals.

One-third of adults with chronic conditions (33%) who have a regular medical doctor or place of care report that a nurse is regularly involved in their care; not as many adults without chronic conditions (28%) report the involvement of a nurse. Few people in both groups report that other types of health care providers, such as dietitians and nutritionists, work in the setting where they receive regular health care (18% of those with chronic conditions, 16% of those with none) (Figure 6).

FIGURE 5
Avoidable visits to emergency departments



9 The majority of all survey respondents who have a regular medical doctor or place of care report that they are “definitely” taken care of by the same medical doctor or nurse each time (81% with chronic conditions, 70% of those with no chronic condition). Many (24% with chronic conditions, 26% with none) report that if they have a question, they are “probably not/ definitely not” able to call and talk to the primary care provider that knows them best.

- › The majority of health care professionals involved in the care of a patient work well together and with the health care system.

Adults with a regular medical doctor or regular place of care give positive ratings to interactions between health care professionals and the health care system. The majority of adults surveyed report that the health care professionals who serve them seem to work well together (89% of those with and without chronic conditions), with other professionals that the individual consults elsewhere, such as pharmacists and physiotherapists (89% with chronic conditions, 83% without), and with other parts of the health care system, such as hospitals and specialists’ offices (89% and 83%, respectively) (Figure 7).

Responsiveness, comprehensiveness, communication, and coordination of primary health care

- › Most adults report that their primary care provider is responsive to their concerns.

More than half of adults with (60%) and without (59%) chronic conditions report that their primary care providers “always” found out what their concerns were, and most say that their providers “always” took their health concerns very seriously (69% of those with chronic conditions, 65% without) (Figure 8).

- › Too few adults with chronic conditions report that they receive a comprehensive array of health promotion and disease prevention services.

Delivery of these services is an important component of primary health care. However, our survey results reveal that too few adults with chronic conditions (37%) “always” get the help they need to make changes in their habits or lifestyle that would improve their health or prevent illness (34% of those with no chronic conditions).

FIGURE 6
Involvement of other health professionals

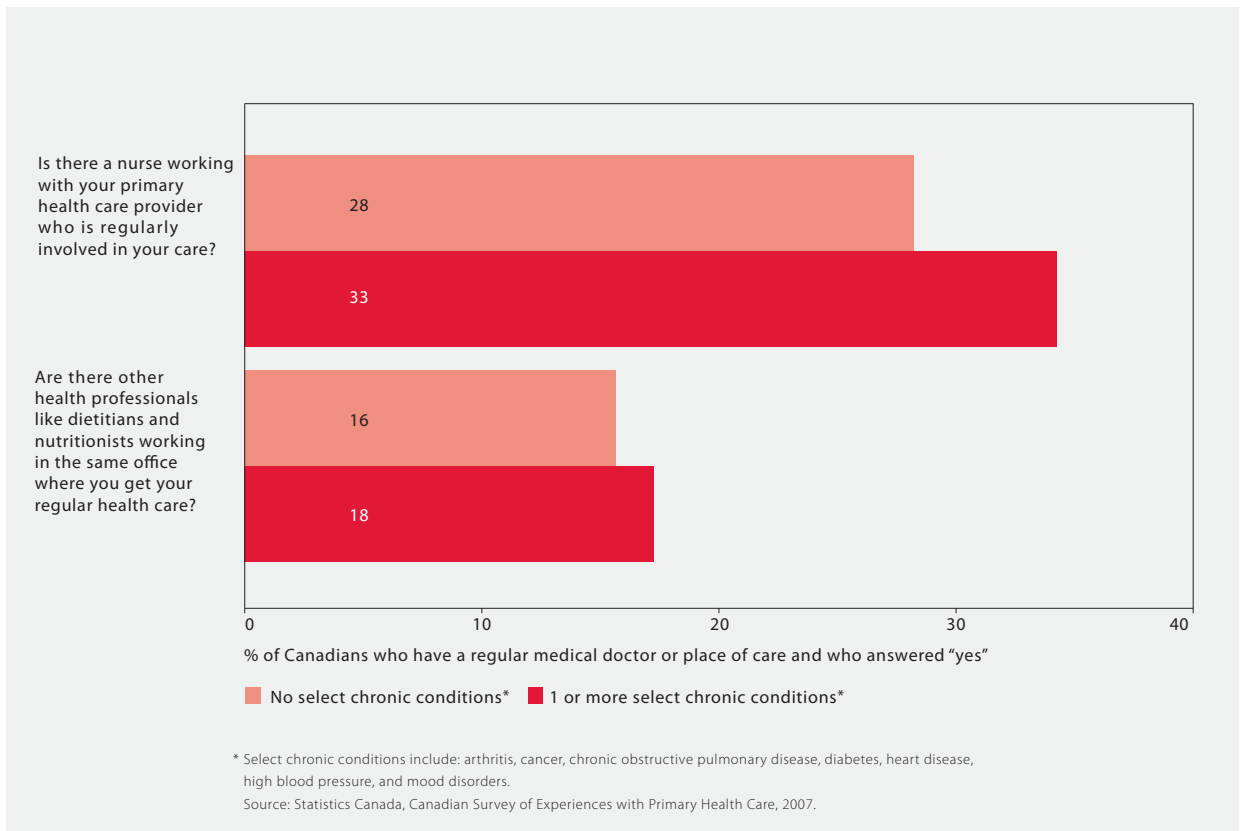


FIGURE 7
Health care provider interactions

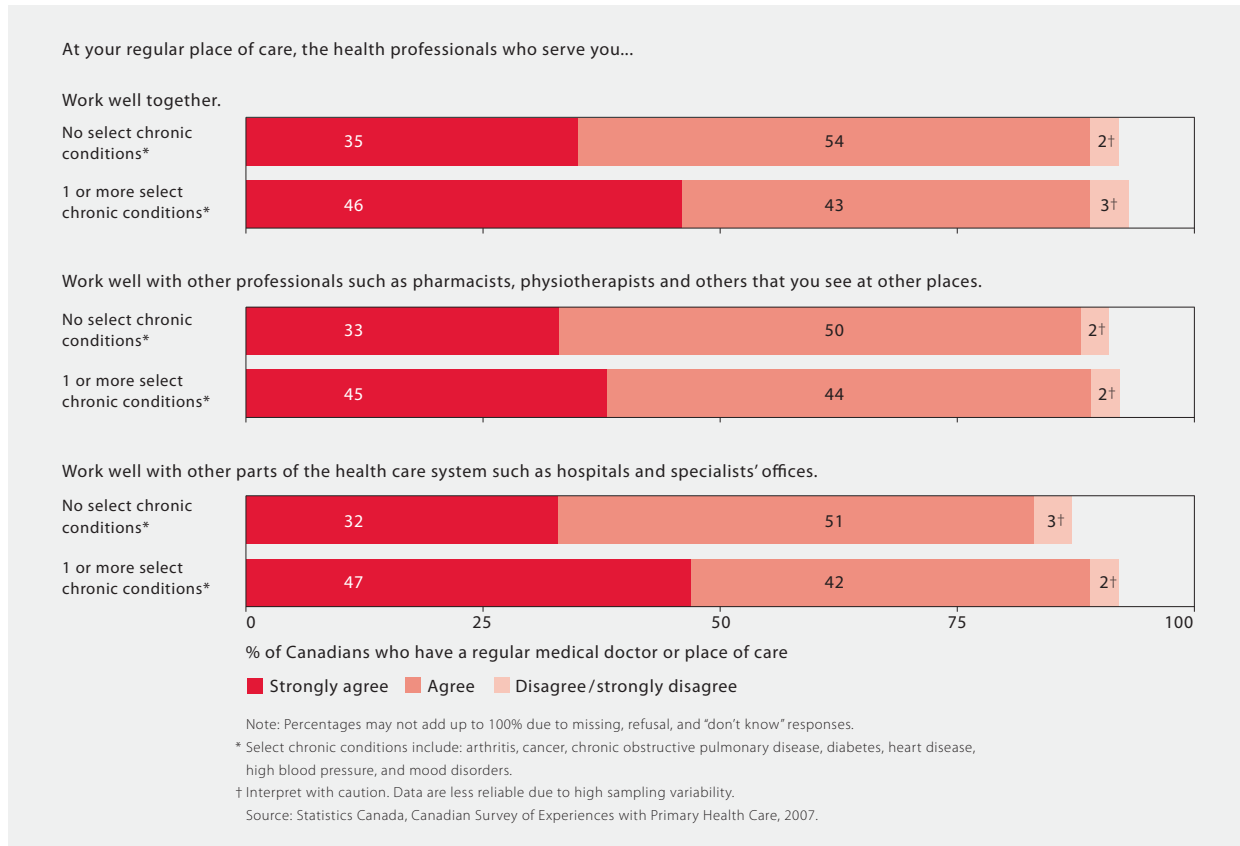
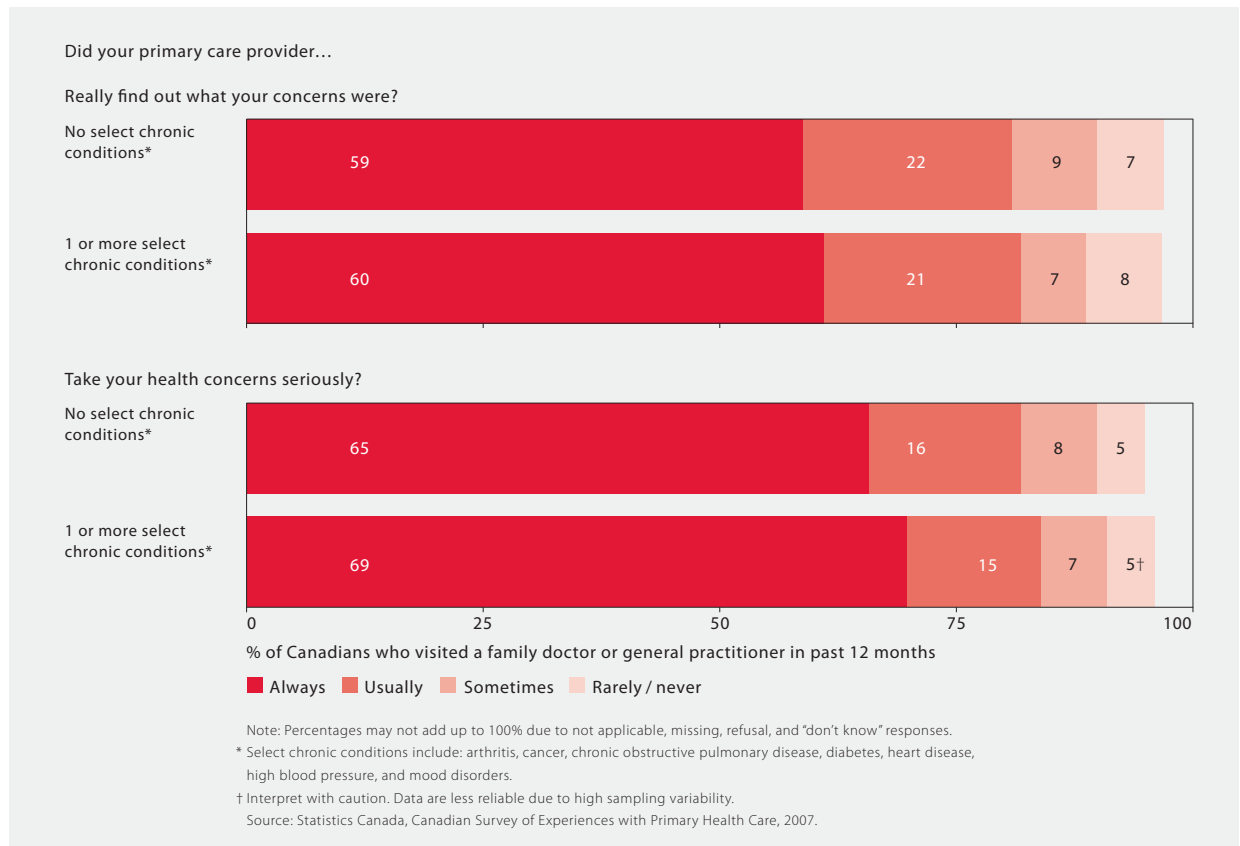


FIGURE 8
Primary care providers' responsiveness to concerns



11

Less than one-third of adults with chronic conditions (30%) say that their primary care providers “always” talk with them about specific things they could do to improve their health or prevent illness, such as quitting smoking, reducing alcohol consumption and stress, exercising, and practising safe sex (24% of those with no chronic conditions). Only one-quarter of adults with chronic conditions (25%) say that their providers “always” give them the help they need to reach or maintain a healthy body weight; this holds true for even fewer adults with no chronic conditions (19%). However, when this question was asked, a large proportion (26% with chronic conditions, 38% without) indicated that this service did not pertain to them (Figure 9).

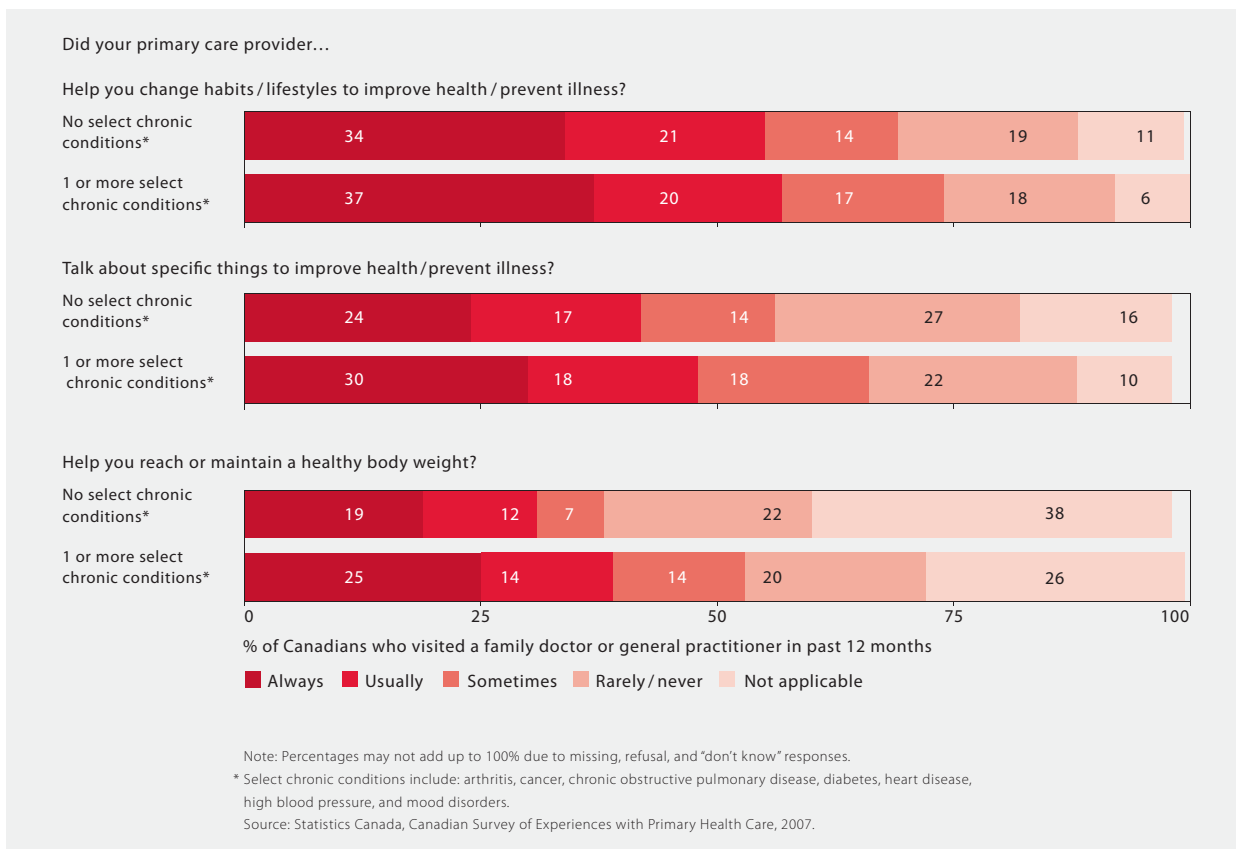
› Overall, half of the adults surveyed report that their regular primary care provider communicates effectively. But far too many report a lack of communication by their doctor and pharmacist regarding medications.

Half of Canadian adults with (51%) and without (56%) chronic conditions report that their primary care providers “never” used words that were hard to understand; most of those with (68%) and without (64%) chronic conditions report that their primary care

providers “never” spoke too fast, and most adults with (74%) and without (70%) chronic conditions report that their primary care providers “always” let them say what they thought was important. Further, many adults in both groups report that when a physical exam (63% with chronic conditions, 49% without) or tests such as blood, x-rays or cancer screening (68% with, 50% without) were conducted, the results were “always” clearly explained (Figure 10).

Just over half of the adults who were taking medications on a regular or ongoing basis (58% with chronic conditions, 55% without) report that, in the past 12 months, their medical doctors or pharmacists “always” explained the side effects of any medication that was prescribed to them. A smaller proportion of adults with chronic conditions who were taking medications (42%) report that, in this same period, their medical doctors or pharmacists reviewed or discussed all the different medications they were using, including medications prescribed by other doctors (27% of those with no chronic conditions reported the same). However, far too many report that this “rarely/never” occurred for all medications they were using (31% of those with chronic conditions, 47% with none) (Figure 11).

FIGURE 9
Primary care providers promote disease prevention and healthy living



- 12 > A majority of adults with chronic conditions report that their care is adequately coordinated.

Canadian adults report having seen multiple medical doctors and specialists in the past year (55% of adults with chronic conditions, 40% with no chronic conditions) and the majority report a high degree of coordination. For example, the majority of adults with chronic conditions (93%) did not think that they had been given duplicate tests (91% of those with no chronic conditions) or that their test results or medical records were unavailable at the time of their scheduled appointment (84% of both groups). Most adults with (78%) and without (75%) chronic conditions also say that they had not received conflicting information from different medical providers or health care professionals (Figure 12).

Whole person care and self-management

- > Less than half of adults with chronic conditions report that services were tailored to address their lifestyles.

Adults with chronic conditions were asked about the care they had received from their primary care providers, specifically regarding their chronic conditions, over the last six months. Almost half (45%) report that they were “almost always/most of the time” asked how their chronic conditions affect their life; a similar proportion (49%) report that they were “almost always/most of the time” asked questions about their health habits. Additionally, 44% report that they were shown that what they did to take care of themselves had influenced their chronic condition.

FIGURE 10
Communicating with your primary care provider

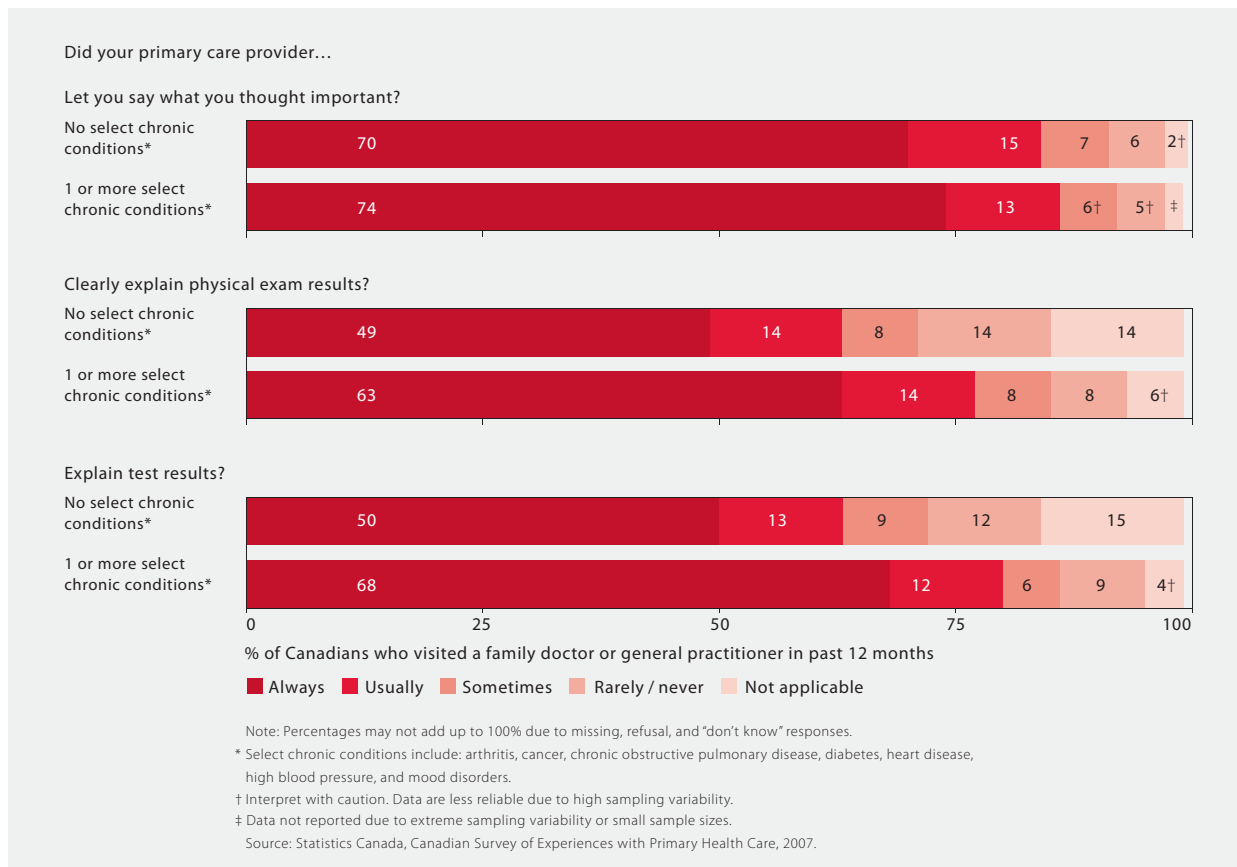


FIGURE 11
Managing prescription medications

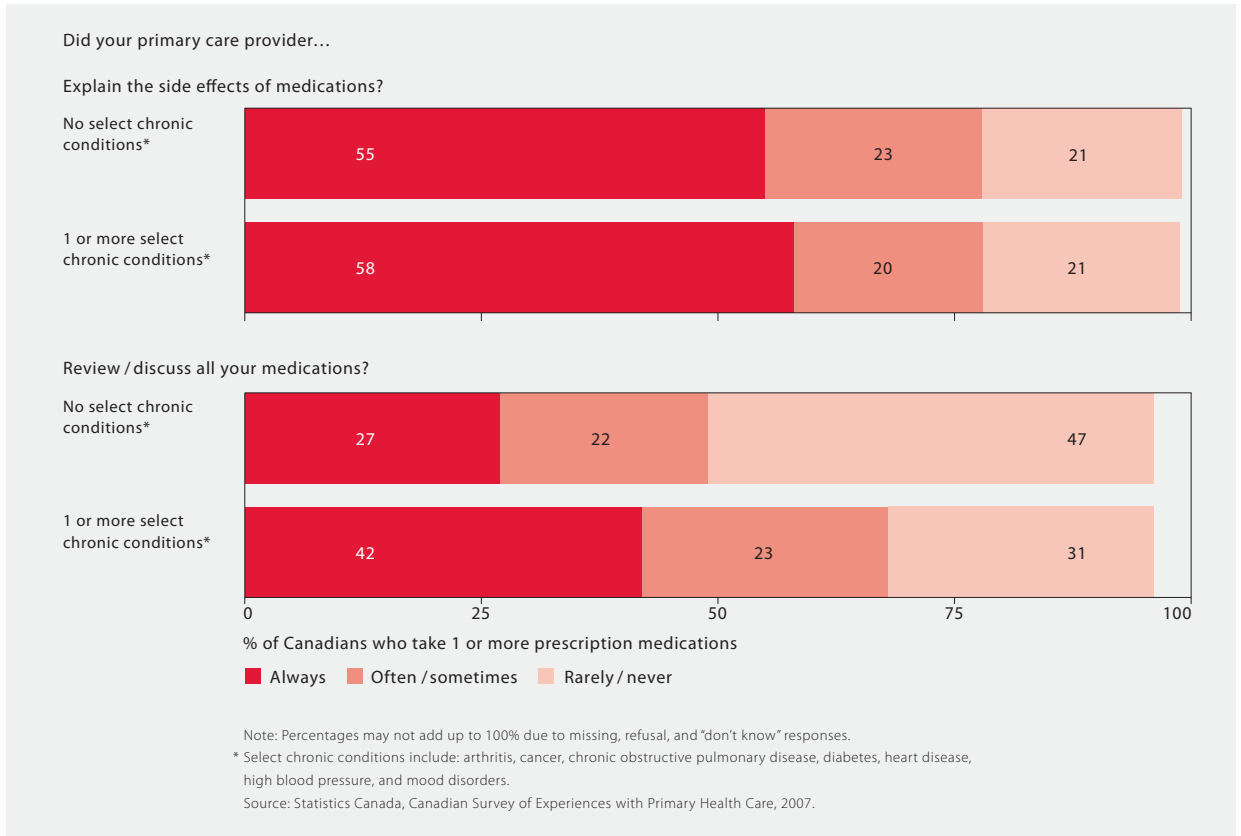
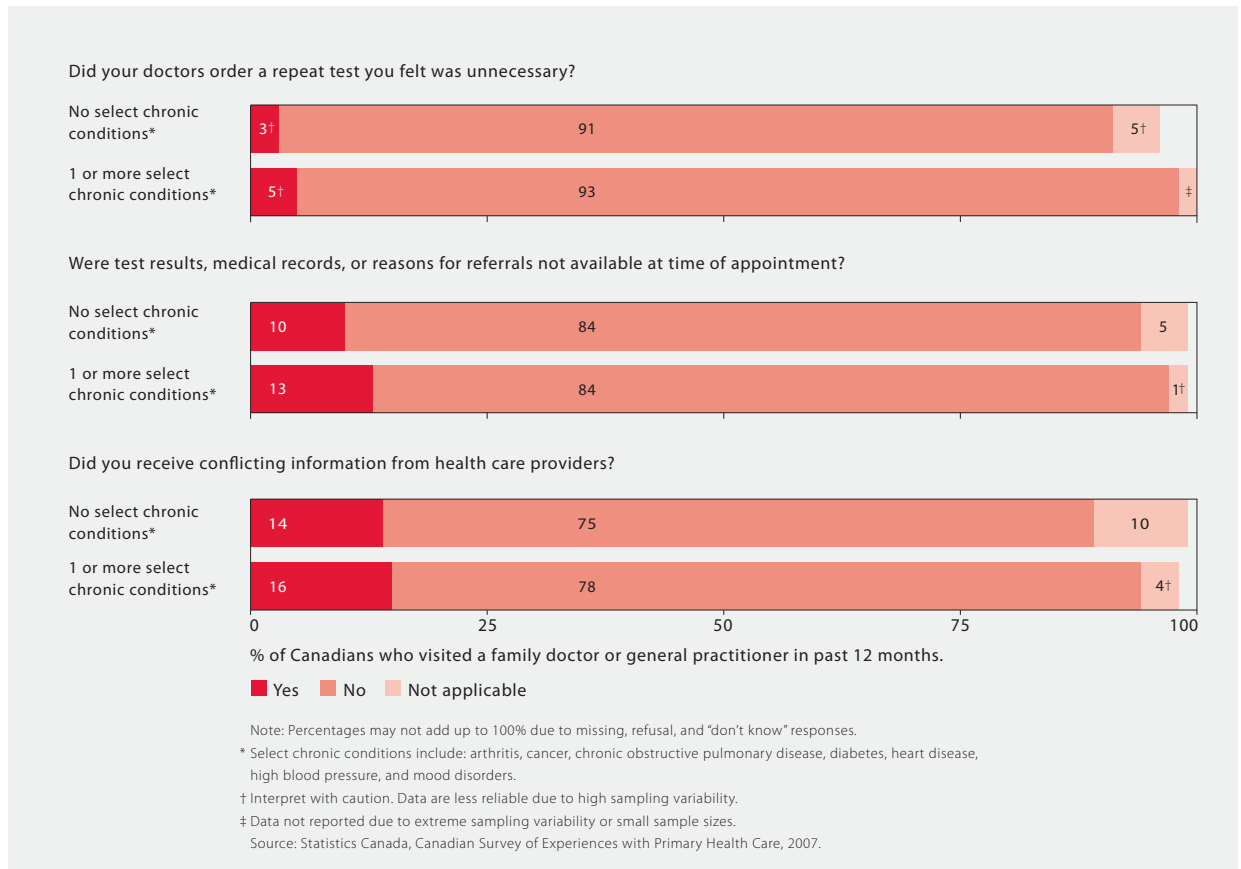


FIGURE 12
Coordinating patient care



Many Canadian adults with chronic conditions (34%) were “almost always/most of the time” asked about their goals in caring for their chronic conditions, and a similar proportion (38%) report that they were “almost always/most of the time” helped to set specific goals to improve their eating or exercise habits. Most of the group with chronic conditions (79%) were “almost always/most of the time” satisfied with the organization of their care (Figure 13).

- › Only half of adults with chronic conditions report that they are adequately involved or engaged in treatment planning and care management.

Many Canadian adults with chronic conditions (44%) report that their primary care providers “almost always/most of the time” helped them make a treatment plan that they could carry out in their daily life. Unfortunately, a full 29% of this group report that they have no such treatment plan (data not shown).

Over half (55%) say that their values and traditions were “almost always/most of the time” taken into account when the treatment was recommended. Among those who received a treatment plan, 50% report that they were “almost always/most of the time” asked for their

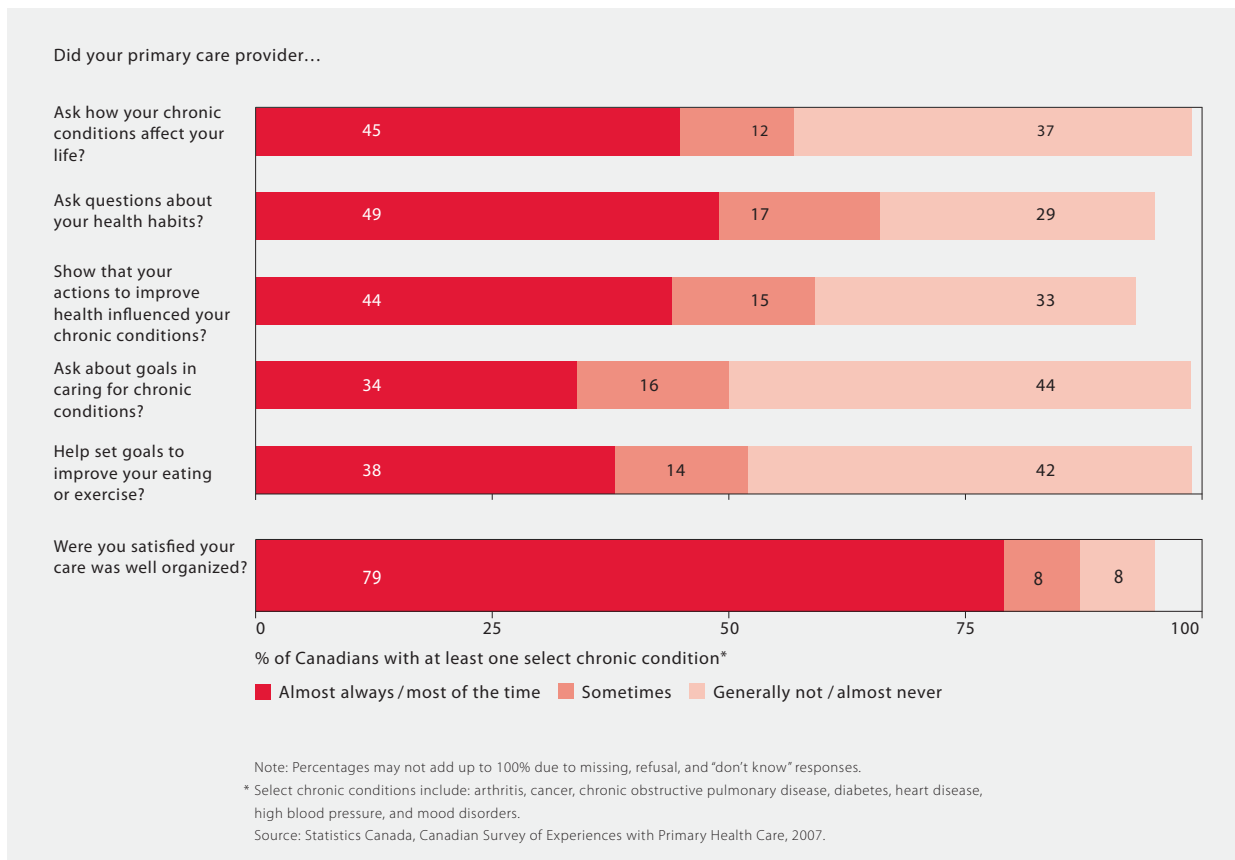
ideas. However, about the same proportion (52%) report that they were “generally not/almost never” given a copy of the treatment plan.

Again, more than half of the surveyed adults with chronic conditions (57%) were “generally not/almost never” given a written list of things to do to improve their health, and 47% were “generally not/almost never” helped to plan so they could take care of their chronic conditions even in difficult circumstances (Figure 14).

- › Too few adults with chronic conditions get connected with educational resources and community supports that might help them manage their own conditions.

About three-quarters were “generally not/almost never” encouraged to go to a specific group or class, such as an educational seminar, to cope with chronic conditions (74%); programs in the community, such as support groups or exercise classes that could help them (70%); or referred to a dietitian, health educator, or counsellor (71%) (Figure 15).

FIGURE 13
Involving patients in chronic illness care: setting goals



15

- › Too few adults with chronic conditions report that they received adequate follow-up care.

Over half of Canadian adults with chronic conditions (57%) report that they were “generally not/almost never” told how visits with other types of doctors, such as specialists or surgeons, helped their treatment; a large proportion were “generally not/almost never” contacted after a visit with their primary care providers to see how things were going (62%) or asked about their visits with other doctors (46%)(Figure 15).

Patient knowledge and confidence in self-management

- › The majority of adults with and without chronic conditions recognize the importance of self-management and report a great deal of confidence in managing their own health care.

Almost all adults with chronic conditions (97%) “strongly agree” or “agree” that when all is said and done, they are responsible for managing their own health (99% of those with no chronic conditions responded this way). Again, almost all (98% of adults with and without chronic conditions) “strongly agree”

or “agree” that taking an active role in their health care is the most important factor in determining their health and ability to function. Similarly, almost all (96% of all adults surveyed) “strongly agree” or “agree” that they are confident in knowing when they need to seek health care and when they can handle a health problem themselves (Figure 16).

Among adults with chronic conditions, the majority “strongly agree” or “agree” that they understand the nature and causes of their health conditions (90%), are aware of how to prevent further problems (88%), are confident to take actions to prevent or minimize symptoms or problems (91%), are confident to figure out solutions when new problems arise with their health condition (85%), and are confident to tell their primary care providers concerns that they have, even without being asked (92%) (Figure 17).

FIGURE 14
Involving patients in chronic illness care: treatment plans

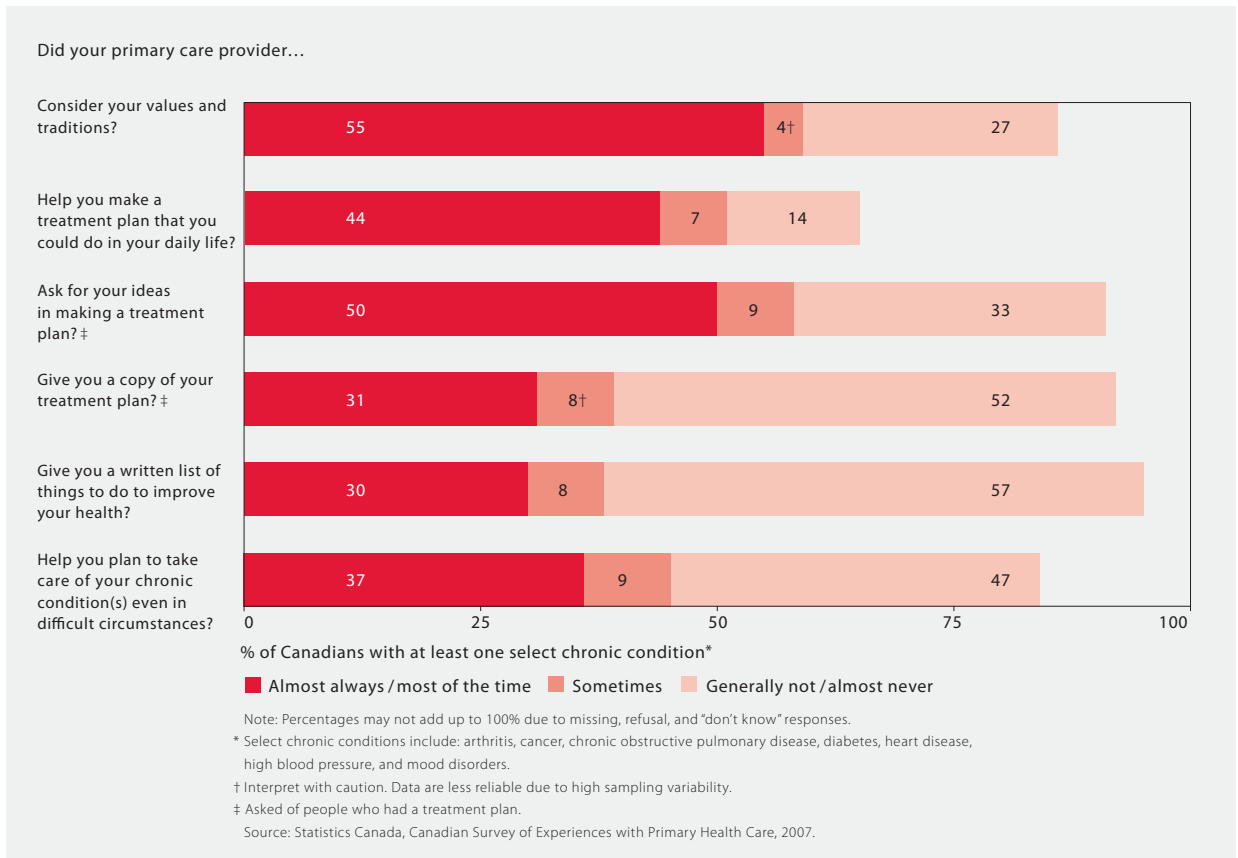


FIGURE 15
Involving patients in chronic illness care: referrals and follow-up

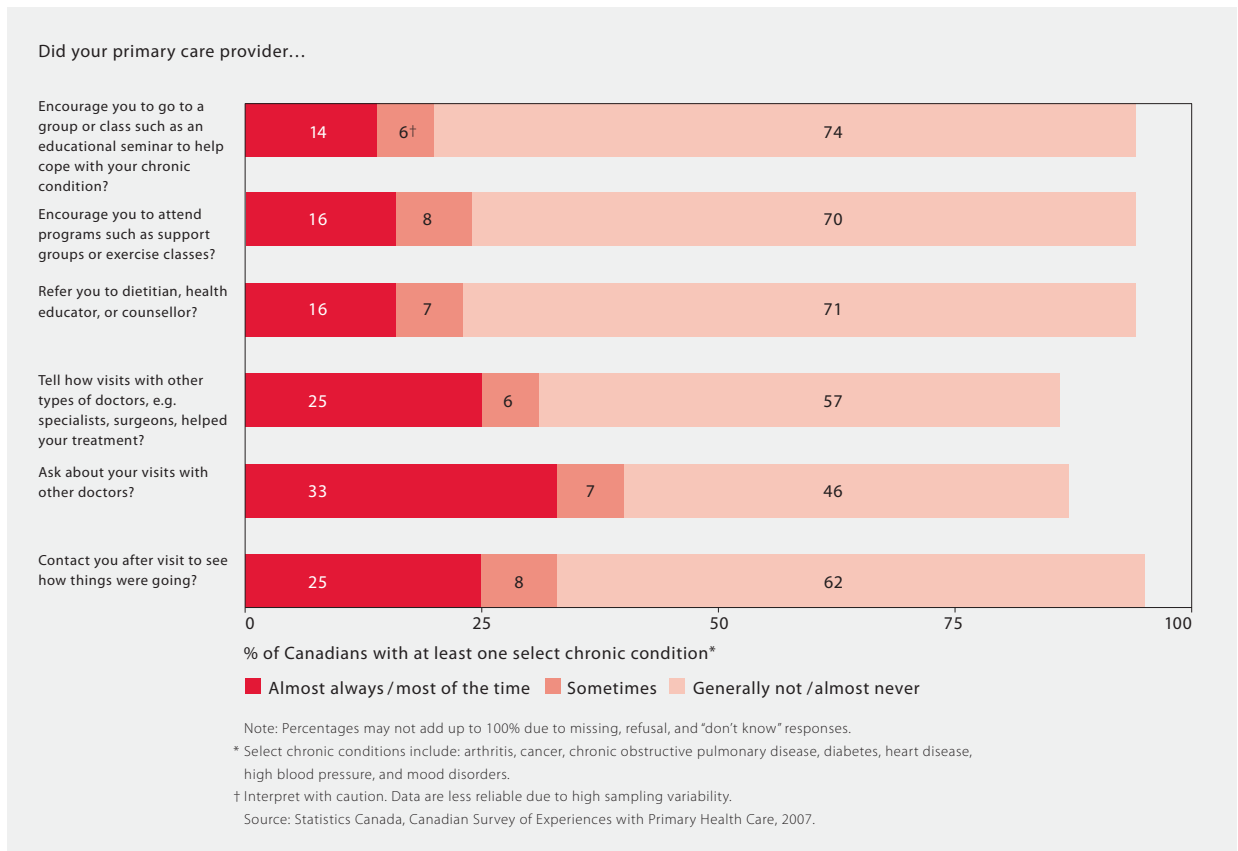


FIGURE 16
Managing your own health

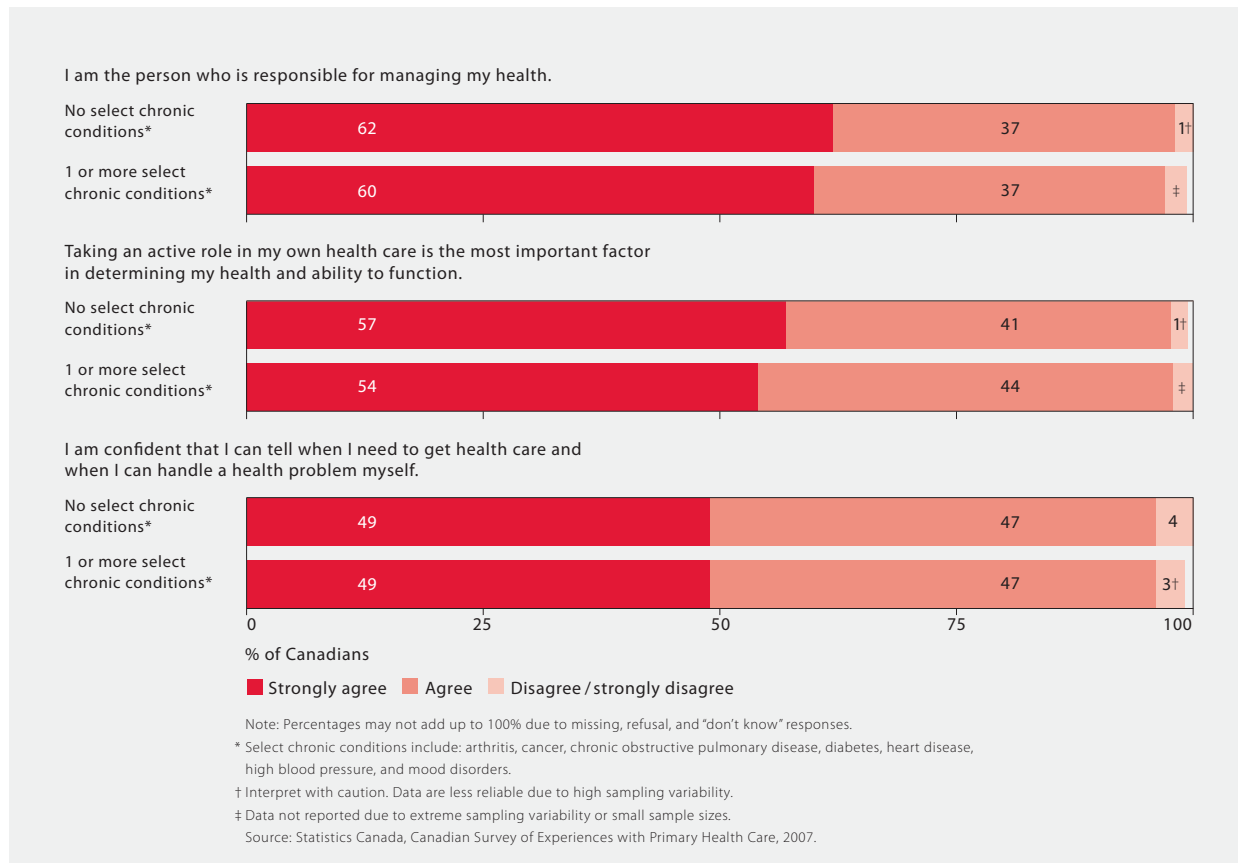
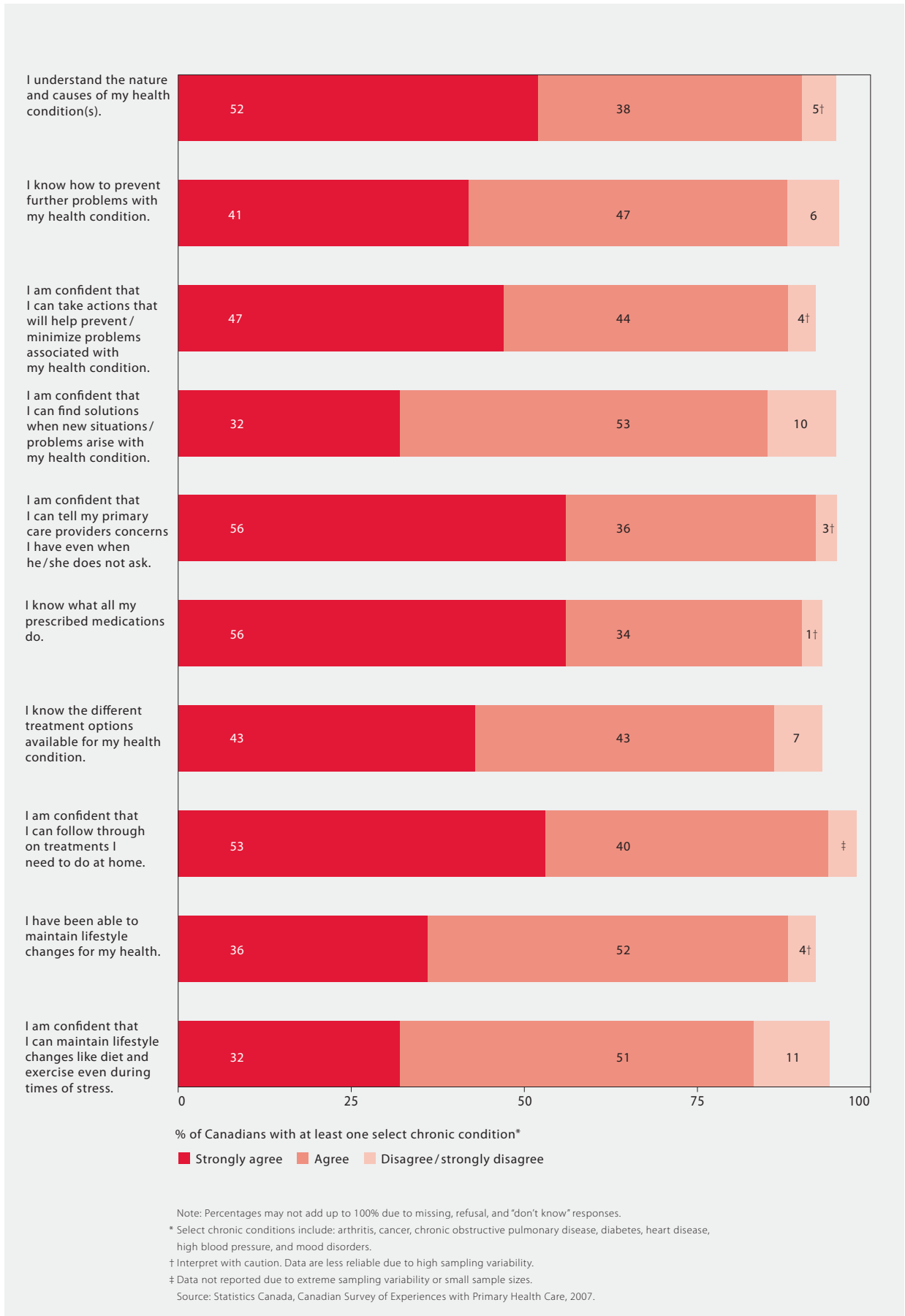


FIGURE 17
Involving patients in chronic illness care: knowledge and confidence



The majority of adults with chronic conditions also feel confident in their knowledge of what each of their prescribed medications does (90% responded “strongly agree” or “agree”), are aware of the different medical treatment options available for their health condition(s) (86%), and are confident in their ability to follow through at home (93%). Further, these people “strongly agree” or “agree” that they have been able to maintain the lifestyle changes they have made to improve their health (88%) and are confident in being able to maintain these changes, such as diet and exercise, even during times of stress (83%) (Figure 17).

Perceived quality of care and confidence in care

- › Most adults with and without chronic conditions give high ratings to the quality of care they receive from their primary care provider, and many are confident that they will get quality care when they need it.

Most adults with chronic conditions (79%) report that the quality of care they have received from their primary health care provider has been either “excellent” or “very good” (70% of those with no chronic conditions felt this way) (Figure 18). Similar proportions (75% and 68%, respectively) say they would “definitely” recommend their primary care provider to a friend or relative.

About one-third of adults with chronic conditions (32%) report a high level of confidence (“very confident”) in getting quality and safe care if they needed it; a smaller proportion of those with no chronic conditions (24%) responded this way (Figure 19). When asked about their confidence in the health care system, half of Canadian adults with (50%) and most without (60%) chronic conditions say that their overall confidence in the system is relatively unchanged (Figure 20). The majority of all adults surveyed (82%) report that the health care system requires some repair (either major repair or minor tuning up).

Additional results from this survey – responses of Canadian adults overall, as well as a breakdown of data specific to seniors (aged 65 and older) – will be available in early 2008 in the Health Council of Canada’s upcoming report on primary health care and home care.

FIGURE 18
Quality of care

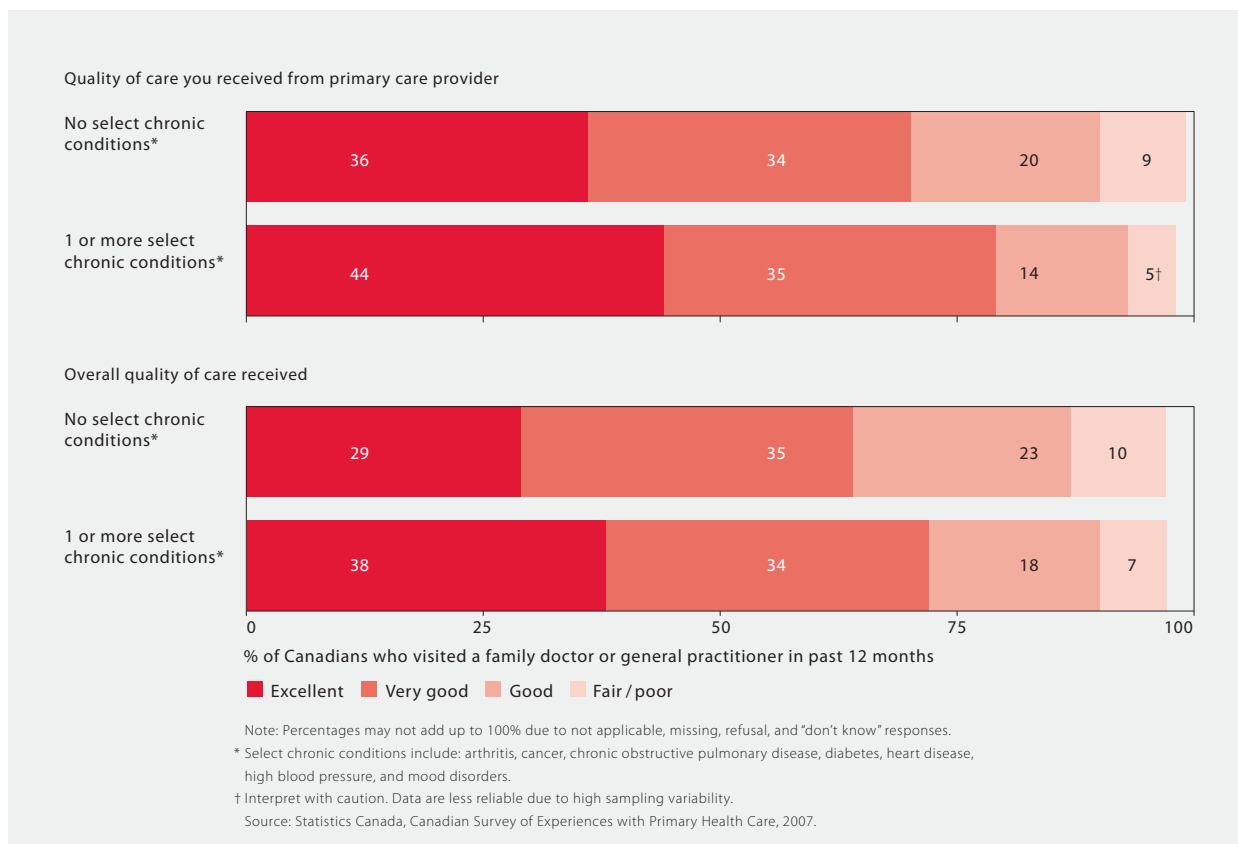


FIGURE 19
Confidence in quality and safety of care

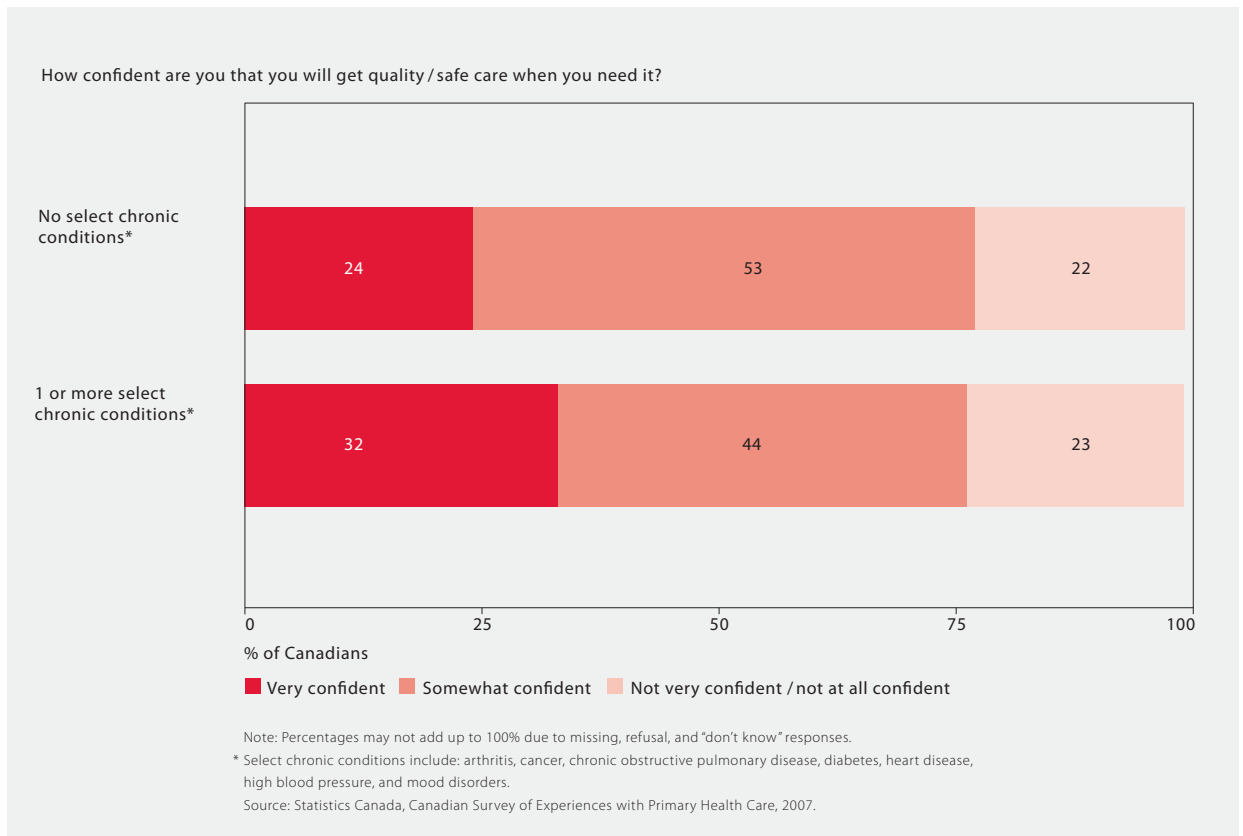
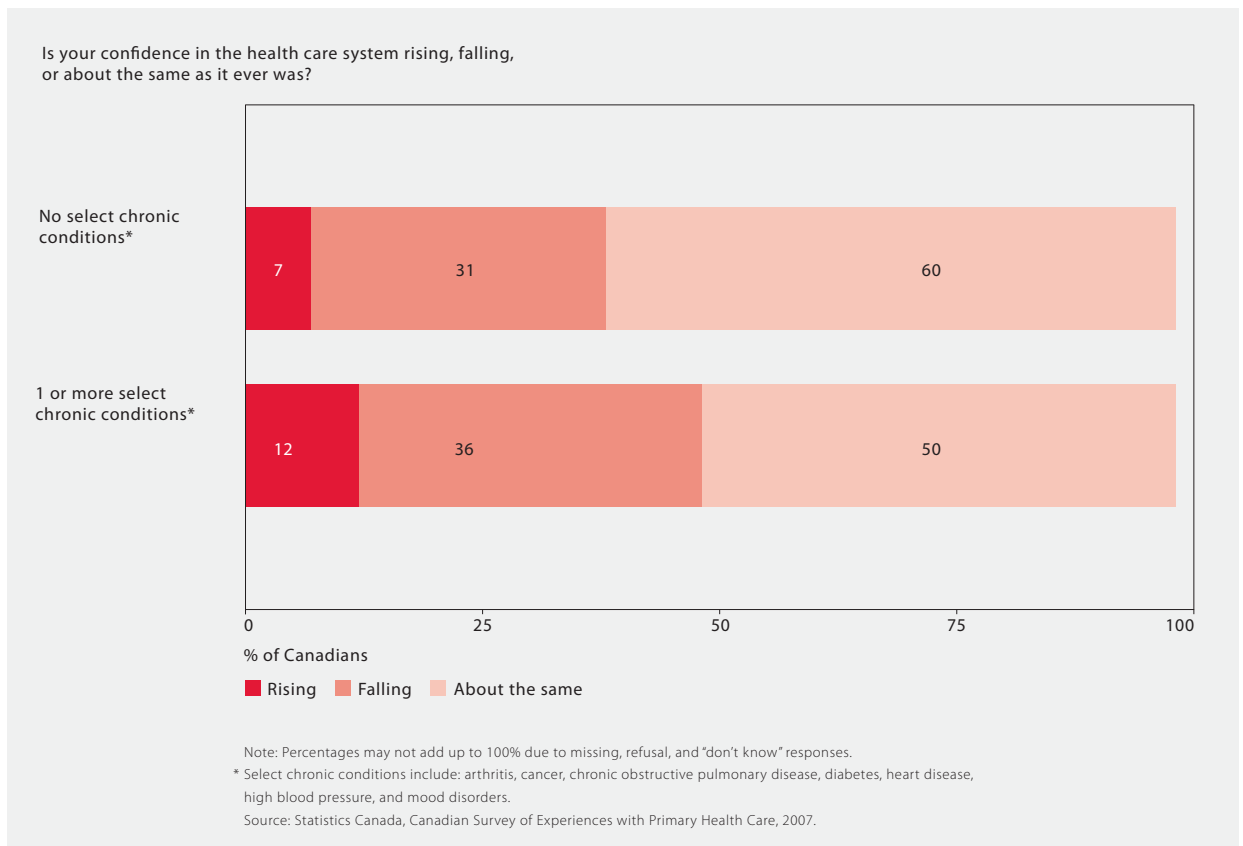


FIGURE 20
Confidence in the health care system



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Canada's First Ministers established the Health Council of Canada in the 2003 *Accord on Health Care Renewal* and enhanced our role in the 2004 *10-Year Plan to Strengthen Health Care*. We report on the progress of health care renewal, on the health status of Canadians, and on the health outcomes of our system. Our goal is to provide a system-wide perspective on health care reform for the Canadian public, with particular attention to accountability and transparency.

The participating jurisdictions have named Councillors representing each of their governments and also Councillors with expertise and broad experience in areas such as community care, Aboriginal health, nursing, health education and administration, finance, medicine and pharmacy. Participating jurisdictions include British Columbia, Saskatchewan, Manitoba, Ontario, Prince Edward Island, Nova Scotia, New Brunswick, Newfoundland and Labrador, Yukon, the Northwest Territories, Nunavut and the federal government. Funded by Health Canada, the Health Council operates as an independent non-profit agency, with members of the corporation being the ministers of health of the participating jurisdictions.

The Council's vision

An informed and healthy Canadian public, confident in the effectiveness, sustainability and capacity of the Canadian health care system to promote their health and meet their health care needs.

The Council's mission

The Health Council of Canada fosters accountability and transparency by assessing progress in improving the quality, effectiveness and sustainability of the health care system. Through insightful monitoring, public reporting and facilitating informed discussion, the Council shines a light on what helps or hinders health care renewal and the well-being of Canadians.

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