FOR THE RECORD

New monitoring for multiple sclerosis

The Canadian Institute for Health Information (CIHI) will develop a national surveillance system to track the symptoms and treatment of people with multiple sclerosis (MS).

Health Minister Leona Aglukkaq announced the Canadian Multiple Sclerosis Monitoring System on Mar. 23 in a bid to improve both the quality of life and care for the estimated 55 000 to 75 000 Canadians who live with the disease. “We need reliable, national data on MS to help those diagnosed with MS and their health care providers,” she said in a news release (www.phac-aspc.gc.ca/media/nr-rp/2011/2011_0323-eng.php).

The new system will collect clinical and demographic information on a voluntary basis from patients with MS through the Canadian Network of MS Clinics. The network’s 22 member clinics are estimated to treat up to 80% of the multiple sclerosis patients in Canada (www.cihi.ca/CIHI-ext-portal/internet/en/Document/types+of+care/primary+health/RELEASE_22MAR11).

CIHI will use that information to help measure disease patterns across the country, identify variations in the use of treatments and monitor the long-term patient outcomes associated with specific treatment options.

The findings of these analyses will be published by CIHI in regular public reports. Researchers will also be able to access the system’s data in a privacy-sensitive manner.

“The more that is understood about the disease, its progression and the use of treatments in this country, the more people with MS can make the best choices about their own care,” said Yves Savoie, president and CEO of the MS Society of Canada, in a news release (http://mssociety.ca/en/releases/nr_2011_0323.htm).

The surveillance system will be developed by CIHI in collaboration with the MS Society of Canada and the Canadian Network of MS Clinics. The Public Health Agency of Canada will provide initial federal funding for the project.

Representatives of multiple sclerosis patients, clinical and technical experts, and provincial and territorial governments will also have input on the system’s design.

“People living with MS will be the ultimate beneficiaries of this monitoring system as it will shed light on important topics like CCSVI [chronic cerebrospinal venous insufficiency], the long-term benefit of current therapies and also serve as an invaluable tool in assisting researchers, health professionals and policy makers in their work,” said Savoie.

Canada has one of the highest rates of multiple sclerosis in the world, according to the MS Society of Canada.

Most people with multiple sclerosis are diagnosed between the ages of 15 and 40. — Lauren Vogel, *CMAJ*

The 6% solutions

Canada’s three primary political parties are vowing to maintain 6% annual increases in federal transfer payments to the provinces for health care once the current intergovernmental Health Accord expires in 2014.

The Conservatives promised to spare health transfers from the budget axe before 2014 while unveiling their campaign platform, *Here for Canada* (www.conservative.ca/media/ConservativePlatform2011_ENs.pdf). “Unlike the previous Liberal government, we will not cut transfer payments to individuals or to the provinces for essential things like health care, education, and pensions,” the platform states.

But spokesperson Ryan Sparrow asserted in an email that the platform vow actually extends to continuation of

the 6% escalator clause once the health accord expires in 2014. The recent federal budget, Sparrow writes, confirmed that the party will extend the escalator clause by providing \$44.7 billion in transfers in 2014–15 and \$47 billion in 2015–16.

The platform itself is not quite as unequivocal about continuation of the escalator clause, stating only that “Canadians expect and deserve timely access to high-quality health care services. To help achieve that goal, we will work collaboratively with the provinces and territories to renew the Health Accord and to continue reducing wait times. In our discussions we will emphasize the importance of accountability and results for Canadians — better reporting from the provinces and territories to measure progress, and guarantees covering additional medically necessary procedures.”

“In the spirit of open federalism, when renewing the Health Accord we will respect the fact that health care is an area of provincial jurisdiction and respect limits on the federal spending power. Recognizing asymmetrical federalism, we will follow the precedent of a separate agreement with the Government of Quebec regarding the implementation of the renewed Health Accord,” the platform adds.

Sparrow, though, writes that continuation of the escalator clause is confirmed on “page 185 of the Budget, table 5.8” (www.budget.gc.ca/2011/plan/Budget2011-eng.pdf).

The Liberal and New Democratic parties, meanwhile, categorically say that if elected, they will maintain the 6% funding escalator clause beyond 2014, when the annual funding increase is scheduled to expire with the current 10-year federal–provincial Health Accord.

The Liberals made their commitment to renew the escalator clause at a 6% level in an open letter to Canadians on Apr. 8 (www.liberal.ca/newsroom

/news-release/open-letter-canadians-future-health-care-michael-ignatieff-leader-liberal-party-canada/).

“The provinces are coping with budgetary deficits and spiraling health care costs. It is critical that a new federal government commits to investing in health care beyond 2014, so that provinces can get on with the job of reforming our health care system. We must ensure it will be there when every Canadian family needs it. For these reasons, a Liberal government will maintain the current 6% health care funding escalator beyond 2014,” the letter states.

“There are many details and variables that the next Government of Canada will need to negotiate. Liberals must first earn the trust of voters, but backing away from health care now would be irresponsible. We can build on the fiscal legacy left behind by Jean Chrétien and Paul Martin’s leadership if we make better choices and turn the page on out-of-control spending like \$6 billion in corporate tax cuts, \$13 billion for US-style mega-prisons, and \$30 billion for untendered stealth fighters,” the letter adds. “All governments will have to work together to do a better job of being accountable to Canadians for results, achieving value for money, and ensuring quality and equality in health care service across the country.”

The New Democrats made an identical commitment to the escalator clause while unveiling their election platform (www.ndp.ca/platform/improve-your-family-health-services). “The accord will guarantee a continued strong federal contribution — including the 6 per cent escalator — to Canada’s public health care system — in return for a clear, monitored and enforced commitment to respect the principles of the Canada Health Act and to the integrity and modernization of health care,” the New Democrat platform states.

The Conservative platform also reiterates a number of measures that were first announced in the federal budget, including a scheme to attract doctors, nurses and nurse practitioners to “under-served rural and remote” communities by forgiving a portion of their Canada Student Loans, and the creation of a nonrefundable family caregiver tax credit to Canadians who provide care to

infirm or dependent relatives, including spouses, common-law partners and children (www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3845).

The platform also vows that, if re-elected, a Conservative government would “ensure that every recreational hockey arena in Canada has a defibrillator, and we will support training for attendants in using them.” — Wayne Kondro, *CMAJ*

New Democrats propose dedicated long-term care transfer payment to provinces

A dedicated federal transfer payment to the provinces for long-term care, and the inclusion of home care and residential long-term care as insured services covered by the Canada Health Act are among election promises included in the New Democratic Party’s “Quality Home Care Plan,” unveiled on the hustings Apr. 6.

A New Democrat government would establish “a dedicated transfer for long-term care” in the renegotiation of the current intergovernmental health accord, which expires in 2014, party leader Jack Layton said in a press release (www.ndp.ca/press/layton-proposes-new-help-for-senior-health-care-0).

In a media backgrounder on their plan, the New Democrats also state that they would also enshrine both home care and residential long-term care as medically necessary services under the Canada Health Act.

“Leading up to the 2014 renegotiation of the health accord, New Democrats will work with the provinces and territories to increase access to a basic level of quality non-profit home care services across the country by enshrining home care within the Canada Health Act,” the New Democrats state, adding that they will also “work with the provinces and territories to extend Medicare to include residential long-term care, with federal funding tied to legislated standards, including Canada Health Act criteria and conditions.”

The New Democrats say that, if elected, they would invest \$500 million

in 2011–12 to allow 100 000 more families to access home care and provide an additional 5000 long-term care spaces across the country. The party would also spend \$37 million to help families modify their homes so that the elderly can remain out of facilities for longer “by doubling the forgivable loan available under the existing Home Adaptations for Seniors’ Independence (HASI) program — from \$3,500 to \$7,000. This program would provide assistance to up to 10,570 individuals and families per year.”

“For five years, Stephen Harper has ignored the health care challenges facing older Canadians,” Layton said. “Our Quality Home Care Plan and new Long-Term Care Initiative will show real leadership on health care for seniors and help families caring for older relatives at home.” — Roger Collier, *CMAJ*

Liberal Party election platform features several health planks

A \$1 billion family care plan featuring six months of employment insurance benefits for those who take time off work to care for family members who are ill; a national brain health strategy and bolstered support for those facing so-called catastrophic drug costs were among health initiatives unveiled in the Liberal party’s election platform.

The platform — *Your Family. Your Future. Your Canada*. — also includes measures aimed at reducing obesity levels and limiting and amount of trans fats and salt that Canadian consume, and would cost Canadians \$8 billion over two years, according to Liberal projections (www.liberal.ca/platform/).

The Grits propose to significantly expand compassionate care benefits under the Employment Insurance system to as much as six months instead of six weeks. They would also eliminate a current eligibility requirement that obliges Canadians to obtain from their doctor a certificate that their relative is “gravely ill with a significant risk of death within 26 weeks.”

“The new program will have more humane eligibility requirements for

family caregivers, changing the nature of the required doctor's certificate," the platform states. "We will build more flexibility into the program by allowing the six months to be claimed in smaller blocks of time over a year-long period and allowing family members to share the six months to provide care. The new Family Care EI Benefit will cost \$250 million per year and will help an estimated 30,000 family caregivers."

The Liberals also propose to introduce a family care tax benefit that would provide Canadians caring for family members in their homes with a tax-free monthly payment to a maximum \$1350 per year. The benefit would "be available to all family caregivers with family incomes under \$106,000 who produce a medical certificate affirming that their ill family member requires a significant amount of personal care and assistance with daily tasks. Families with sick children who meet the criteria will also qualify. The new Family Care Tax Benefit will help an estimated 600,000 family caregivers each year at an annual cost of \$750 million."

The Liberal's proposed "Canadian Brain Health Strategy" would include \$100 million over two years for research into "new treatments and therapies for neurological disorders, and accelerating progress in understanding, treating and preventing brain diseases"; a public education campaign "to encourage good brain health throughout life, including better understanding of how proper diet, physical and mental exercise slow down the decline of brain health," and to reduce the stigma associated with brain disease; and legislative measures to prevent discrimination based on genetic testing.

The Liberal platform fell short of calling for a national pharmacare or a national catastrophic drug cost program. However, it does say that a Liberal government would "work with the provinces and territories to ensure that all Canadians from coast-to-coast-to-coast have a drug plan that covers the cost of prescription drugs for illnesses such as cancer, diabetes or arthritis that can be financially catastrophic to families."

The Liberals also said they will reduce obesity levels by implementing

a "Canadian Health Promotion Strategy" that would include "setting national targets for physical activity in primary and secondary schools" and establishing a "Canada's first National Food Policy, a comprehensive set of measures designed to fulfill the simple, yet powerful goal of putting more healthy Canadian food on Canadian plates." To that end, the Liberals propose to set aside \$80 million over four years to encourage Canadians to buy their food locally, as well as \$50 million over four years to bolster food inspection capabilities at the Canadian Food Inspection Agency. The Grits also indicated they would introduce "strong new regulatory standards on trans fats and salt."

The platform also claimed that a Liberal government would improve current inequities in the availability of health care in rural areas but offered no specifics other than to say it would "work with provinces, territories and health professionals to pursue solutions." — Lauren Mitsuki, Ottawa, Ont.

Report blasts "collective irresponsibility" in French drug regulation

France's drug regulation system requires a massive overhaul to improve the safety, efficacy and transparency of its decision-making process, say state inspectors in a scathing report to the country's president.

The 85-page tome, *Rapport de la mission sur la refonte du système Français de contrôle de l'efficacité et de la sécurité des médicaments*, highlights the "total collapse" of the Agence française de sécurité sanitaire des produits de santé (AFSSAPS), describing the public health agency as a "heavy, slow-moving, (and) unresponsive ... gas factory" reined in by fear of litigation from drug companies and rife with conflicts of interest (<http://lesrapports.ladocumentationfrancaise.fr/BRP/114000141/0000.pdf>).

President Nicolas Sarkozy commissioned the report in the wake of the public health disaster caused by the appetite suppressant benfluorex hydrochloride (Mediator), which

French regulators allowed to remain on the market some 10 years after other countries had banned it. Between 500 and 2000 people in France are believed to have died because of its adverse effects.

The report indicates the scandal was not an "isolated incident" but the product of longstanding and systemic failure on the part of AFSSAPS "to identify and investigate" serious adverse events "within a reasonable period of time."

A large part of that failure the report puts down to incompetence, conflicts of interest and a lack of transparency among the many thousands of "experts" who inform AFSSAPS' regulatory process.

"It would be better to have a few independent, competent, decisive and responsible experts than an army of shadow experts," many of who are "ignorant of the dossiers on which they're voting," the report states.

Furthermore, "one is not an expert on the pretext that one has received an expert dossier, but one receives such a dossier because one is a recognized expert."

The report also blasts AFSSAPS for failing to make expert hearings public and for applying the precautionary principle in reverse, readily approving "a lot of unnecessary medication" while "almost always refusing to suspend or withdraw drugs that are more dangerous than useful."

To remedy these problems, the report suggests "thorough reforms, a real turning point" be made to ensure:

- ethics that privilege the interests of patients over those of industry;
- "functionalism" in adapting the structures of the health agencies to their goals;
- medicalization of authority, by giving doctors and pharmacists the principal role and responsibility in the direction and actions of medical regulatory bodies;
- greater scientific and clinical competence among advising experts, who should be whittled down to the best 20 to 40 individuals from a current cast of thousands;
- more "sober" judgment from physicians to avoid overprescribing drugs;
- greater independence of health agencies, their experts and leaders,

“without concessions to conflicts of interest”;

- creation of a “sunshine act” to promote greater transparency about conflicts of interests and industry gifts to health officials;
- increased responsiveness in pharmacovigilance;
- more accountability among experts for the decisions they make, to put an end to the “collective irresponsibility of quasi-anonymous commissions”;
- requirements that clinical trials and the pharmaceutical industry, wherever possible, compare new drugs to those already existing on the market and provide proof of their added value and safety.

On the latter score, the report states drugs “contributing nothing more than the previous treatments” should be denied reimbursement. — Lauren Vogel, *CMAJ*

Editor’s note: report translated by Lauren Vogel, *CMAJ*

New Democrats propose health care overhaul

A series of measures aimed at reining-in pharmaceutical costs, a promise to eliminate fee-for-service delivery of health care, and initiatives to bolster the number of physicians trained in Canada are among health care promises unveiled by the New Democratic Party in their election platform.

Other planks include previously announced policies to establish a dedicated federal transfer payment to the provinces for long-term care, and to include home care and residential long-term care as insured services covered by the Canada Health Act (www.cmaj.ca/earlyreleases/4theRecord.dtl).

The platform states that if elected and “as finances permit,” a New Democrat government would pursue various initiatives to reduce the cost of medications (www.ndp.ca/platform/improve-your-family-health-services#section-3-1). Those would include “improved assessment to ensure quality, safety and cost and health effectiveness of prescription drugs; using bargaining power in pharmaceutical purchases; cutting administrative costs through

public administration; establishing science-based formularies and clinical guidelines to advance evidence-based practice by physicians; more aggressive price review; eliminating kick-backs from pharmaceutical companies to pharmacists; (and) moving towards more publicly funded research and development, driven by public priorities, not commercial profits.”

The platform offers little in the way of detail as to how the New Democrats will reform fee-for-service payment models for physicians other than to say that they would “take appropriate steps to replace fee-for-service delivery.” The change is part of a section on renegotiating a new 10-year health accord in which the New Democrats vow they would maintain a 6% escalator clause for federal health transfer payments to the provinces.

The New Democrats also state that if elected, they would train 1200 doctors over the next 10 years and 6000 nurses over six years, while “substantially increasing the number of training spaces for other health professionals.” As well, the New Democrats say they would broaden the physician demographic with “programs aimed at recruiting and supporting low-income, rural and aboriginal medical students.”

The New Democrats would also introduce a program to cover 50% of a maximum cost of \$35 000 for renovating family homes to include self-contained spaces for senior family members. They would also expand local and provincial programs to provide healthy meals to schoolchildren, as well as introduce legislation obliging the federal government to establish guidelines on treating and monitoring concussions and other sports-related injuries. — Samia Madwar, Ottawa, Ont.

More doctors working after retirement age

Fears that baby boomer doctors will retire en masse causing severe shortages in Canada’s physician supply may be unfounded.

A third of physicians aged 65 years or older are still working full time, according to a Canadian Institute for

Health Information (CIHI) study, *Putting Away the Stethoscope for Good? Toward a New Perspective on Physician Retirement* (http://secure.cihi.ca/cihiweb/products/HHR%20Physician%20Report_En_Web.pdf).

Moreover, older doctors who are no longer classified as working full time still carry, on average, 40% of a full workload.

“With so many doctors about to reach their so-called retirement years, some Canadians have expressed concern about whether they will continue to have access to the medical services they need in the coming years,” Michael Hunt, CIHI director of pharmaceuticals and health workforce information services, said in a news release (www.cihi.ca/CIHI-ext-portal/internet/en/Document/spending+and+health+workforce/workforce/physicians/RELEASE_07APR11). “Our study shows that physicians do not tend to retire, in the conventional sense, when they reach age 65.”

There were roughly 68 100 active physicians working in Canada in 2009, 12% of who were 65 and older, up from 9% five years earlier.

Rather than leave the workforce completely, the report found many of these older physicians simply cut back their clinical practice. More than 7% of physicians aged 55 and older, and some 12% of those aged 65 and older, became minimally active in 2007. That means they worked a third or less of their previous workload.

“In the physician workforce, retirement is not a sudden event,” Dr. Raymond Pong, author of the study and researcher at the Centre for Rural and Northern Health Research at Laurentian University in Sudbury, Ontario, said in the news release. “Instead, we see a transition to retirement, with doctors progressively taking on less work and carefully choosing the work that they do take on. It’s a process that can extend over months and, in some cases, years.”

As doctors aged, they were less likely to engage in such activities as hospital inpatient care, obstetrics, anesthesia and services requiring advanced procedural skills.

Fewer than 35% of female family physicians aged 65 to 69 provided hos-

pital inpatient care, compared to 59% of those younger than 40. Similarly, 56% of male family physicians aged 65 to 69 provided services requiring advanced procedural skills, compared with 77% of those aged 40 to 44. This shift in scope of practice happened faster among female physicians than their male counterparts.

While more than 3% of physicians surveyed in 2007 reported that they planned to retire in each of the two years following the survey, CIHI estimates the actual retirement rates were significantly lower, with less than 1% of doctors retiring annually during that period.

"In addition, thanks to an influx of new medical school graduates, the number of active physicians working in Canada is on the rise, and the average age of physicians is stabilizing," said Hunt. — Lauren Vogel, *CMAJ*

Government commitment needed to close gaps in cancer care

Canadians continue to face unnecessary barriers to accessing the cancer care and support they need, including prevention programs and physician advocacy, patient activists argue.

Canada's dearth of breast cancer prevention programs, declining support for clinical trials, underutilization of nurse practitioners and pharmacists in cancer care and poor physician advocacy are among barriers highlighted in the Cancer Advocacy Coalition of Canada's *2010-2011 Report Card on Cancer in Canada* (www.canceradvocacy.ca/reportcard/2010/2010-2011%20REPORT%20CARD%20ON%20CANCER%20IN%20CANADA.pdf).

"As health professionals, we're working against discouraging odds to adjust to increasing constraints, shifting priorities, growing caseloads and a lack of capital and human resources. We shouldn't have to fight the system to get our patients the diagnostics and treatments we know they desperately need," Dr. Pierre Major, cochair of the coalition's board of directors and report card committee chair, said in a news

release (www.canceradvocacy.ca/reportcard/2010/News%20Release.pdf).

Unveiled in the midst of the federal election campaign, the report criticizes the lack of dedicated cancer prevention programs in Canada, particularly for women at high risk of breast cancer.

While preventive lifestyle and medical interventions could reduce the number of new breast cancer cases by several thousand each year, the report estimates such programs are currently aimed at only 5% of at-risk women.

It recommends increased government support for preventive programs to educate women about lifestyle factors that can increase their risk of breast cancer, as well as additional monies to provide women with access to medical interventions such as antiestrogen and anti-inflammatory drugs.

The report also notes that there is declining financial support for clinical trials that could improve outcomes for cancer patients and increase their access to potentially effective new treatments.

Less than 7% of Canadian adults with cancer are currently enrolled in such trials. In some provinces, cancer patient participation in clinical trials has decreased by as much as 28% since 2007.

The report calls for long-term financial commitments from governments to make clinical trials part of standard treatment for cancer patients, as well as relaxed regulatory requirements and timelines for conducting the trials to attract industry investment.

To address shortages in cancer specialists, the report also argues that pharmacists and nurses practitioners should have a greater role in conducting patient assessments, prescribing cancer drugs and ordering laboratory tests.

The report also criticizes the use of formal or informal fidelity agreements between oncologists and their institutional employers to stifle physician advocacy. It calls on professional bodies to increase education and financial support for physician advocacy activities.

The report notes that an estimated 173 800 new cases of cancer occurred in Canada last year. It says 40% of Canadian women and 45% of men will develop cancer during their lifetime. — Lauren Vogel, *CMAJ*

Liberals propose health summit

A Liberal government would convene a first minister's conference within 60 days of taking office to negotiate systemic health reforms and new funding arrangements for health care once the current inter-governmental financing arrangement expires in 2014.

"The purpose of the meeting would be to launch work on new federal-provincial-territorial arrangements for health care funding, and system-wide reforms that will contain costs and improve service to Canadians," Liberal Party leader Michael Ignatieff said in press release (www.liberal.ca/newsroom/news-release/michael-ignatieff-commits-ministers-meeting-health-care-reform-60-days-liberal-government/).

"There's no time to waste — we need to work with the provinces and territories right away on a new funding arrangement that will allow for reforms like enhanced home care and more comprehensive, affordable drug coverage,"

"Mr. Harper's record on health care speaks for itself — he hasn't put a dime of new spending into health care above the commitments Paul Martin made in the 2004 Health Accord, and he's not once met the First Ministers on the subject of health care in five years," Ignatieff added. "That's the record of a government that doesn't care about Canadians' health and isn't serious about a federal role in our health care."

"Stephen Harper's budget said that health care funding was 'subject to change' and he hasn't made any commitment to health funding beyond two additional years. With \$11 billion in new cutbacks and billions in new spending on corporate tax cuts, jails and fighter jets, Stephen Harper's poor choices place long-term sustained funding for health care at serious risk."

Ignatieff reaffirmed an earlier Liberal promise to maintain an annual 6% increase in federal transfer payments to the provinces for health and argued that such "sustained, stable funding will provide the foundation for system-wide reforms." But he provided little in the way of detail about what

such reforms might entail, other than to say they would involve home care and drug coverage. “Better drug coverage and better home care services will also help contain costs for the system, by reducing overall drug costs and easing demand for costly spaces in hospitals.”

In an open letter to Canadians issued in tandem with the press release, the Liberals suggest that they view the federal government’s primary role in systemic reform is to disseminate information about innovations and best practices.

“All provinces are struggling with the challenges of containing costs while delivering quality, accessible, free Medicare. They will have a strong partner in a Liberal government. It’s in the best interests of Canadians that their governments work together effectively,” the open letter states (www.liberal.ca/newsroom/news-release/open-letter-canadians-future-health-care-michael-ignatieff-leader-liberal-party-canada/). “That partnership starts with a commitment to quality, innovation and best practices. We need to do a much better job learning across jurisdictions, based on evidence, and what works. Many exciting innovations in health care management are being tried out in most provinces. But too often they remain confined to just that one place. The federal government is very well-equipped to help spread lessons learned nation-wide, working with all governments.”

“Experts tell us that sharing and implementing best practices can improve quality and save money,” the letter adds. “This will also help ensure that taxpayers get full value for the money already in the system. A key example: the Canadian Medical Association is leading a charge to put the ‘patient first’ in health care management. It’s about giving the system back to the patient. Different provinces are approaching this idea in different ways. All jurisdictions need to be learning from each other — finding out what works best through experience, and

sharing that experience as widely as possible.” — Wayne Kondro, *CMAJ*

More research needed on sexual and gender minority health

The tendency of health studies to treat sexual and gender minorities as a single homogenous group has painted an “incomplete picture” of their health status and needs, argues a landmark report on lesbian, gay, bisexual and transgender (LGBT) health from the United States Institute of Medicine.

The report, *The Health of Lesbian, Gay, Bisexual and Transgender (LGBT) People: Building a Foundation for Understanding*, sketches a series of research and data collection initiatives — including the routine collection of sexual orientation and gender information through federal surveys and electronic health records — that authors say are needed to better identify and understand the health conditions that affect LGBT people (http://books.nap.edu/catalog.php?record_id=13128#toc).

Existing research is “sparse” and “unevenly” conducted, with more research on gay men and lesbians, and less on bisexual, transgender and other subpopulations, the report indicates. Most research has overlooked racial and ethnic differences within the LGBT community and has focused on the health of LGBT adults, with fewer studies on adolescents and seniors.

“It’s easy to assume that because we are all humans, gender, race, or other characteristics of study participants shouldn’t matter in health research, but they certainly do,” Robert Graham, chair of the committee that wrote the report and professor of family medicine and public health sciences at the University of Cincinnati in Ohio, said in a news release (www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=13128). “Routine collection of information on race and ethnicity has expanded our

understanding of conditions that are more prevalent among various groups or that affect them differently. We should strive for the same attention to and engagement of sexual and gender minorities in health research.”

The report sets an agenda for “essential” research needed to form a fuller understanding of LGBT health issues, including:

- demographic data across the life course and subpopulations;
- information on the role social structures — such as families, schools and workplaces — play in the lives and health of LGBT people;
- data on the health care inequities LGBT people face; and
- transgender-specific research, including the health implications of hormone use.

Because LGBT people are a minority of the population, it is often difficult for researchers to recruit sufficient numbers for their studies to yield meaningful data. It’s also difficult for researchers to synthesize data when existing studies and surveys use a variety of definitions as to who is included in specific category groups.

Among measures proposed to resolve such challenges are that federally funded surveys begin to routinely collect data on sexual orientation and gender identity.

The report also calls on the National Institutes of Health to support the development of standardized measures of orientation and gender for use in surveys and other methods of data collection, and to use its policy on the inclusion of women and racial and ethnic minorities in clinical research as a model to encourage grant applicants to address how future studies will include or exclude LGBT groups.

Information on sexual orientation and gender identity should also be collected through electronic health records, the report says, provided that privacy concerns can be satisfactorily addressed. — Lauren Vogel, *CMAJ*

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