

MYALGIC ENCEPHALOMYELITIS / CHRONIC FATIGUE SYNDROME AND FIBROMYALGIA

FINDINGS FROM

THE 2014 CANADIAN COMMUNITY HEALTH SURVEY



The National ME/FM Action Network is a Canadian registered charity established in 1993 and dedicated to helping people who suffer from Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and/or Fibromyalgia through support, advocacy, education and research.

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The following statistics on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia are compiled from the 2014 Canadian Community Health Survey. Information on 17 other chronic conditions as well as the total Canadian Population is also shown.

HIGHLIGHTS

- In 2014, over 400,000 Canadians had a diagnosis of ME/CFS and over half a million had a diagnosis of Fibromyalgia. Combined, this represents over 800,000 Canadians diagnosed with one or both of the conditions (2.7% of the survey's target population).
- ME/CFS and Fibromyalgia are illnesses with high levels of disability, health care utilization, unmet health care needs, unmet home care needs, poverty, food insecurity and social isolation.
- People with ME/CFS and Fibromyalgia are predominantly female. Most are of working age, a time when people are supposed to be participating in family, work and community activities and saving for retirement.

The issues raised by these statistics indicate that ME/CFS and Fibromyalgia have a major impact on Canadian society and need to be addressed.

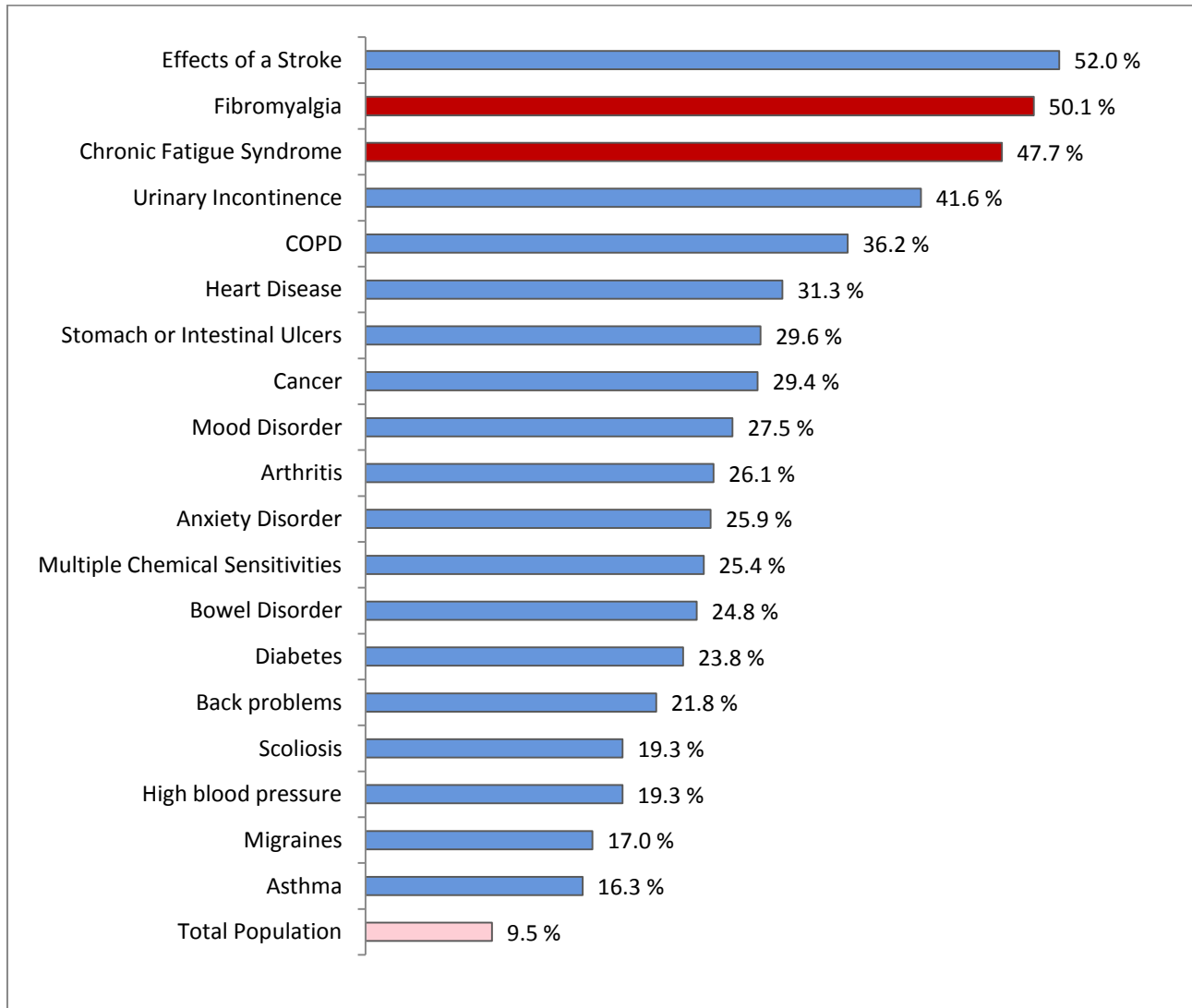
Prevalence of ME/CFS and FM among Canadians Aged 12 and Older, 2014

Chronic Condition	No. with Condition	% with Condition
ME/CFS	407,600	1.4
Fibromyalgia	518,800	1.7
ME/CFS and/or Fibromyalgia	808,700	2.7

Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File

DISABILITY

Canadians Aged 12 and Older Needing Help with Tasks According to their Chronic Health Condition, 2014



Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File

COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)

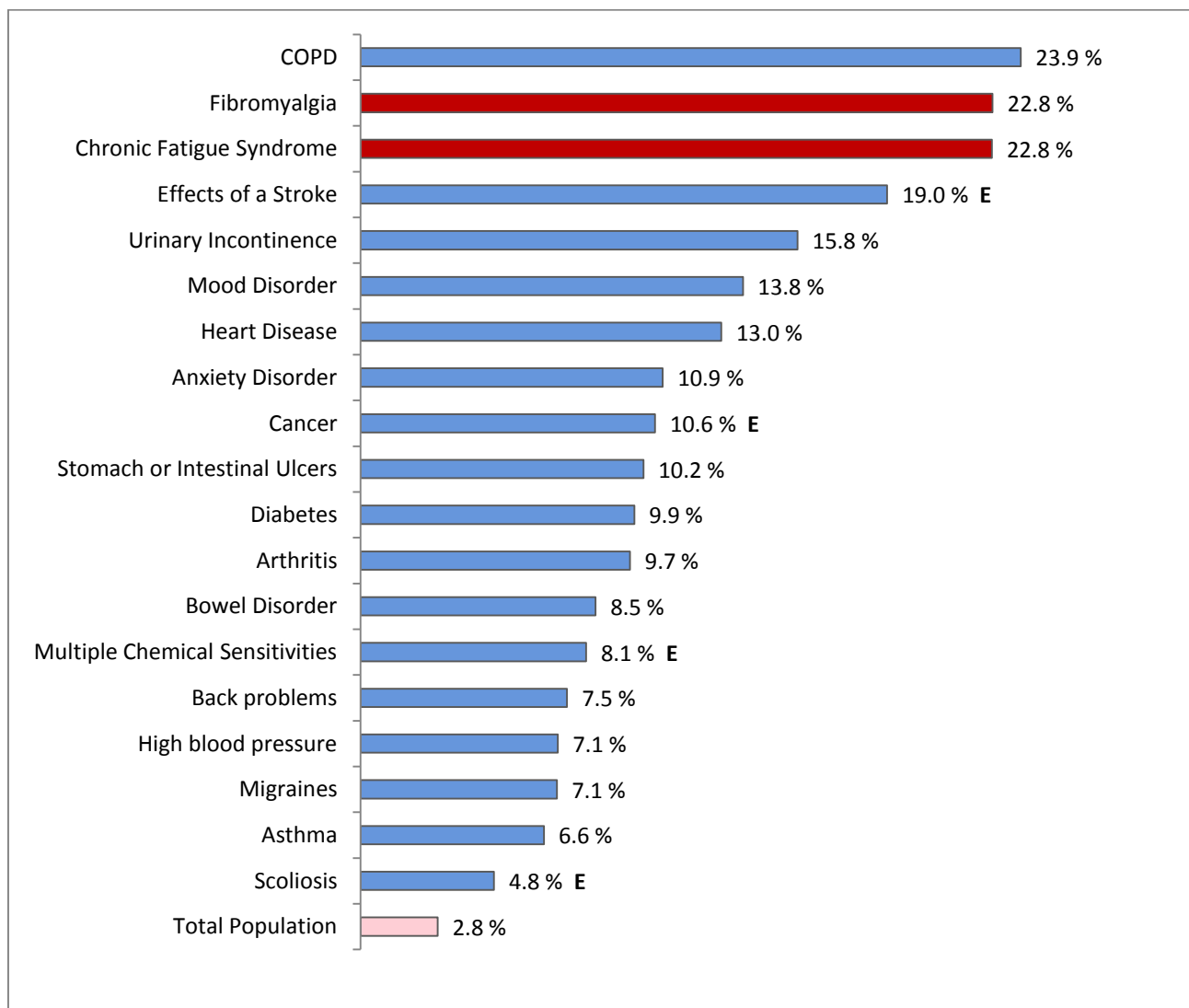
Arthritis = ages 15+; COPD = ages 35+; Urinary Incontinence = ages 25+

Needing help with tasks is comprised of six activities of daily living: needs help preparing meals, getting to appointments/running errands, doing housework, personal care, moving about inside the house, and looking after personal finances.

People reporting ME/CFS or Fibromyalgia are, on average, younger than people with many of the conditions shown. The high rate of needing help with tasks indicates a premature loss of self-reliance and independence among people with ME/CFS or Fibromyalgia.

DISABILITY

Canadians Aged 18-64 who are Permanently Unable to Work According to their Chronic Health Condition, 2014



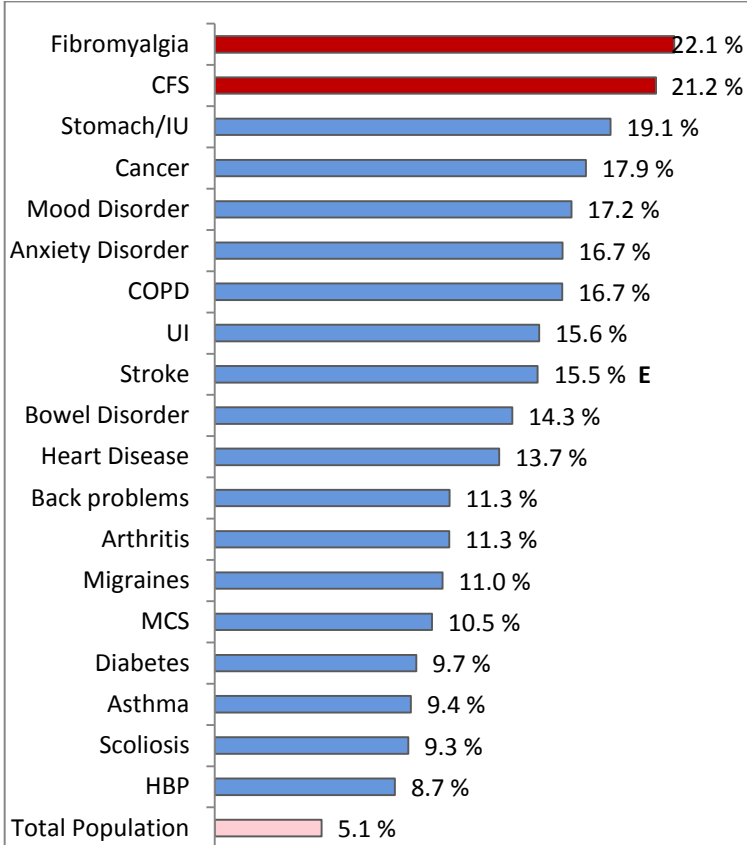
Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File
 COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)
 COPD = ages 35+; Urinary Incontinence = ages 25+
 E = Use with caution (Coefficient of Variation between 16.6% and 33.3%)

High rates of being permanently unable to work among people with ME/CFS or Fibromyalgia highlight significant functional impairment associated with these conditions. It may also reflect a lack of accommodation in work places. In 2014, the number of people aged 18 to 64 with ME/CFS, Fibromyalgia or both reporting they are permanently unable to work was approximately 118,700, which constitutes 19.4% of Canadians permanently unable to work in this age group. The implications for the Canadian economy are substantial in terms of both lost productivity and the need to provide income support.

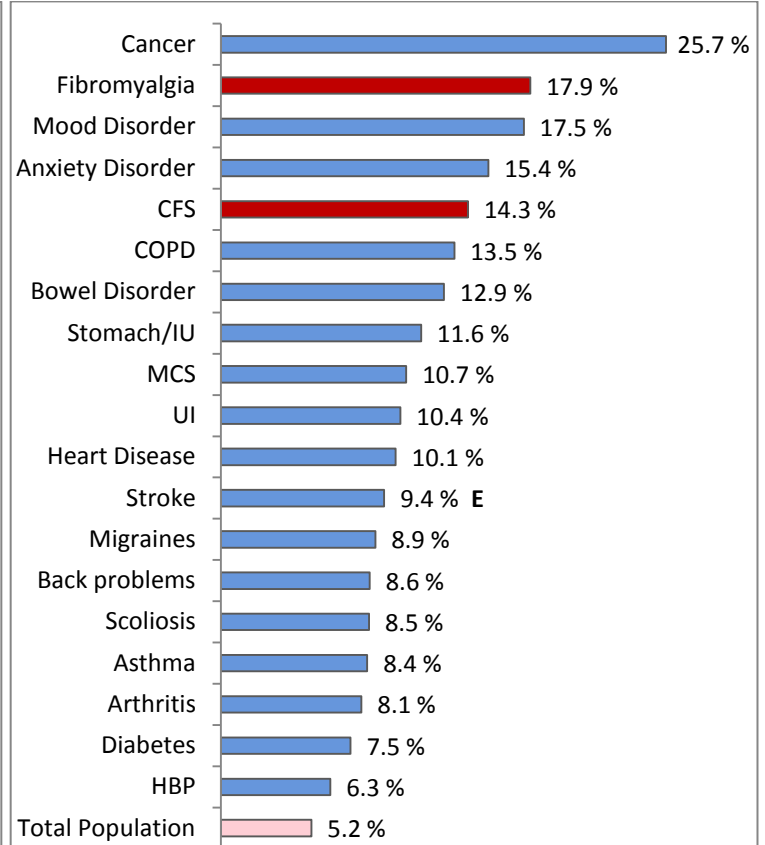
HEALTH CARE UTILIZATION

Health Care Consultations by Canadians Aged 12 and Older in the Previous 12 Months According to their Chronic Health Condition, 2014

10 + Consultations with a Family Doctor



5+ Consultations with a Specialist/Other Doctor



Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File

CFS = Chronic Fatigue Syndrome

COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)

IU = Intestinal Ulcers

UI = Urinary Incontinence

MCS = Multiple Chemical Sensitivities

HBP = High Blood Pressure

Stroke = Effects of a Stroke

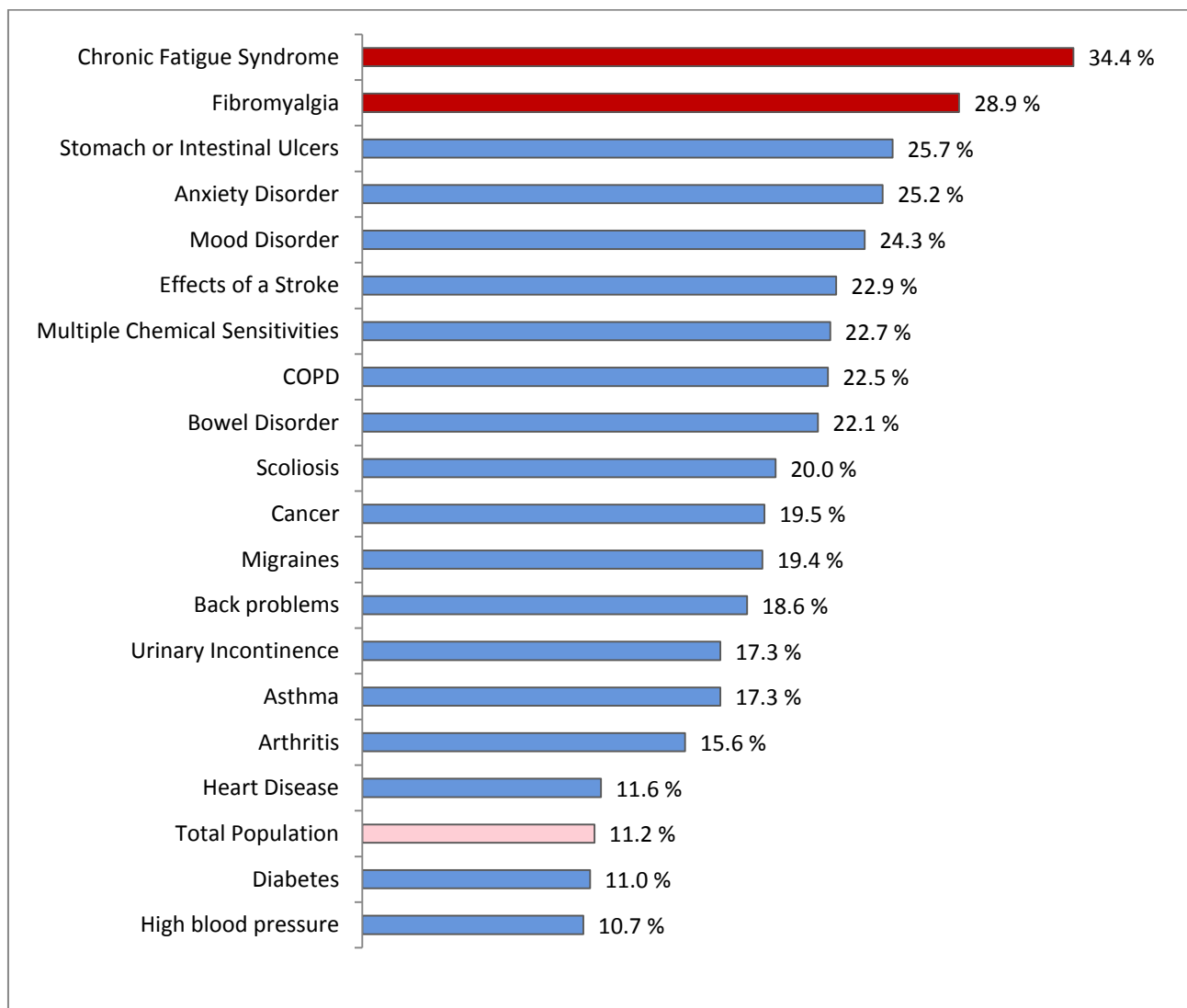
Arthritis = ages 15+; COPD = ages 35+; Urinary Incontinence = ages 25+

E = Use with caution (Coefficient of Variation between 16.6% and 33.3%)

Over 90% of people with ME/CFS or Fibromyalgia consulted a doctor at least once in the previous 12 months while only about 80% of the total population did so. The graphs show that people with ME/CFS and Fibromyalgia often make multiple doctor visits. ME/CFS and Fibromyalgia are complex chronic conditions that can affect multiple body systems and frequently occur in conjunction with other conditions. Despite their heavy use of medical resources, people with ME/CFS or Fibromyalgia report high levels of unmet health care needs.

UNMET HEALTH CARE NEEDS

Canadians Aged 12 and Older Reporting Unmet Health Care Needs According to their Chronic Health Condition, 2014

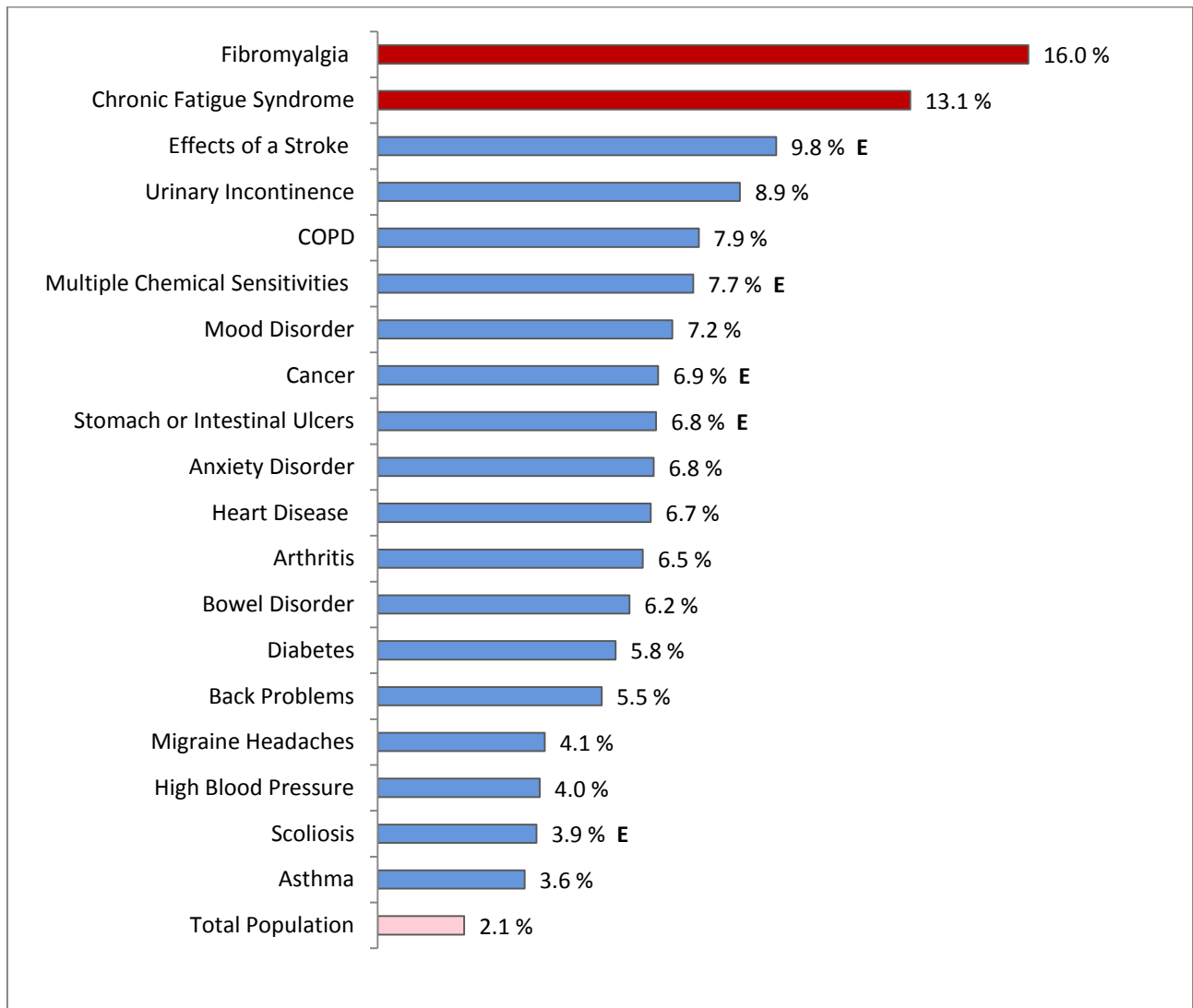


Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File
 COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)
 Arthritis = ages 15+ , COPD = ages 35+; Urinary Incontinence = ages 25+

High rates of unmet health care needs among people with ME/CFS or Fibromyalgia, despite the high rates of physician consultations, suggest that people with these conditions are receiving inappropriate or ineffective care. People with ME/CFS or Fibromyalgia often have difficulty finding health professionals to diagnose and provide care, leading to poor health outcomes and poor quality of life. The rates of unmet health care needs for other chronic conditions are lower than those for ME/CFS and Fibromyalgia, suggesting that the rate of unmet needs for ME/CFS and Fibromyalgia could be reduced by undertaking appropriate training or policy initiatives.

UNMET HOME CARE NEEDS

Canadians Aged 18 and Older Reporting Unmet Home Care Needs According to their Chronic Health Condition, 2014



Source: Statistics Canada, Canadian Community Health Survey, 2014, Master Data File

COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)

COPD = ages 35+; Urinary Incontinence = ages 25+

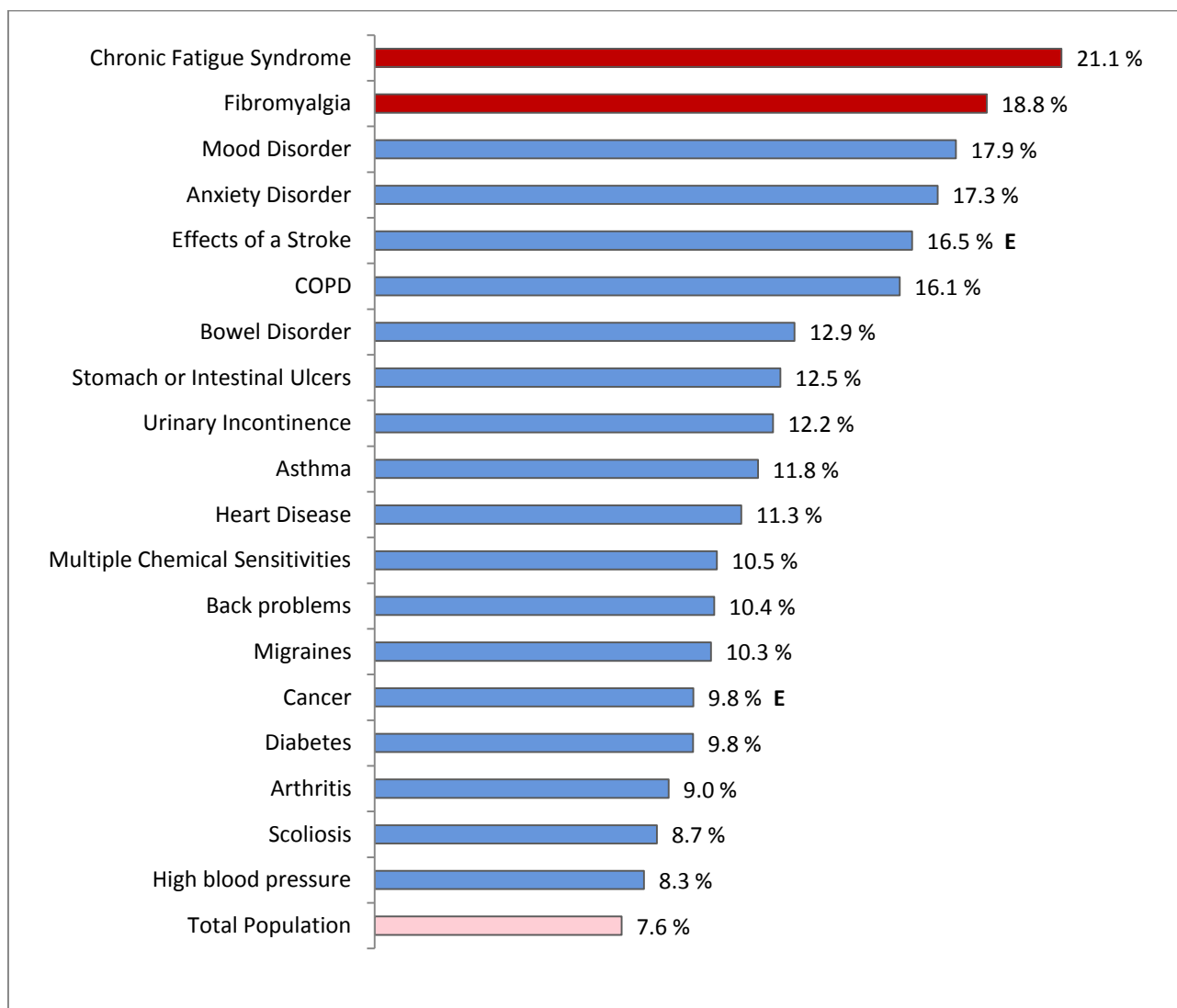
E = Use with caution (Coefficient of Variation between 16.6% and 33.3%)

Respondents from Ontario, Quebec, Prince Edward Island

These findings suggest that despite the high levels of disability among people with ME/CFS or Fibromyalgia, they are having difficulty obtaining home care support. ME/CFS and Fibromyalgia are poorly recognized and understood chronic conditions. Their seriousness appears to be underestimated when home care services are allocated, suggesting that the home care allocation process requires review.

SOCIAL IMPACT

Canadians Aged 12 and Older Reporting a Very Weak Sense of Community Belonging According to their Chronic Health Condition, 2014



Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File

COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)

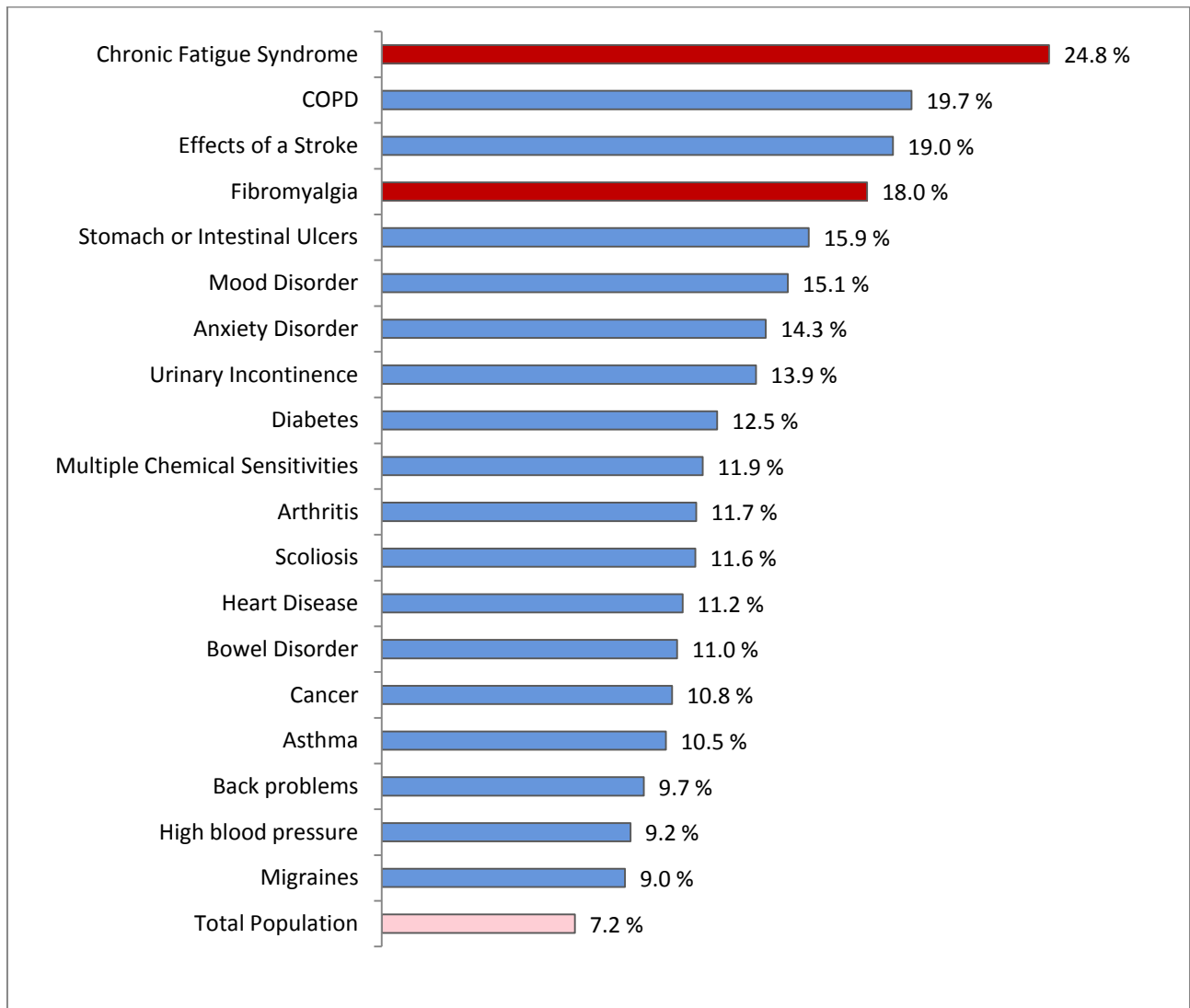
Arthritis = ages 15+; COPD = ages 35+; Urinary Incontinence = ages 25+

E = Use with caution (Coefficient of Variation between 16.6% and 33.3%)

Canadians with ME/CFS or Fibromyalgia are experiencing high rates of having a very weak sense of community belonging compared to other chronic condition groups. ME/CFS and Fibromyalgia are highly disabling conditions and people with these diagnoses can be bedridden, housebound or able to get out only on a limited basis, resulting in an inability to participate in regular activities. People aged 80 or older also experience a high level of disability, but only 7.3% of them report a very weak sense of community belonging. This shows that disability does not invariably lead to social isolation. The reasons why people with ME/CFS and Fibromyalgia feel such a weak sense of community belonging need to be identified and addressed.

HOUSEHOLD INCOME

Canadians Aged 12 and Older Reporting Household Income Less Than \$20,000 Per Year According to their Chronic Health Condition, 2014

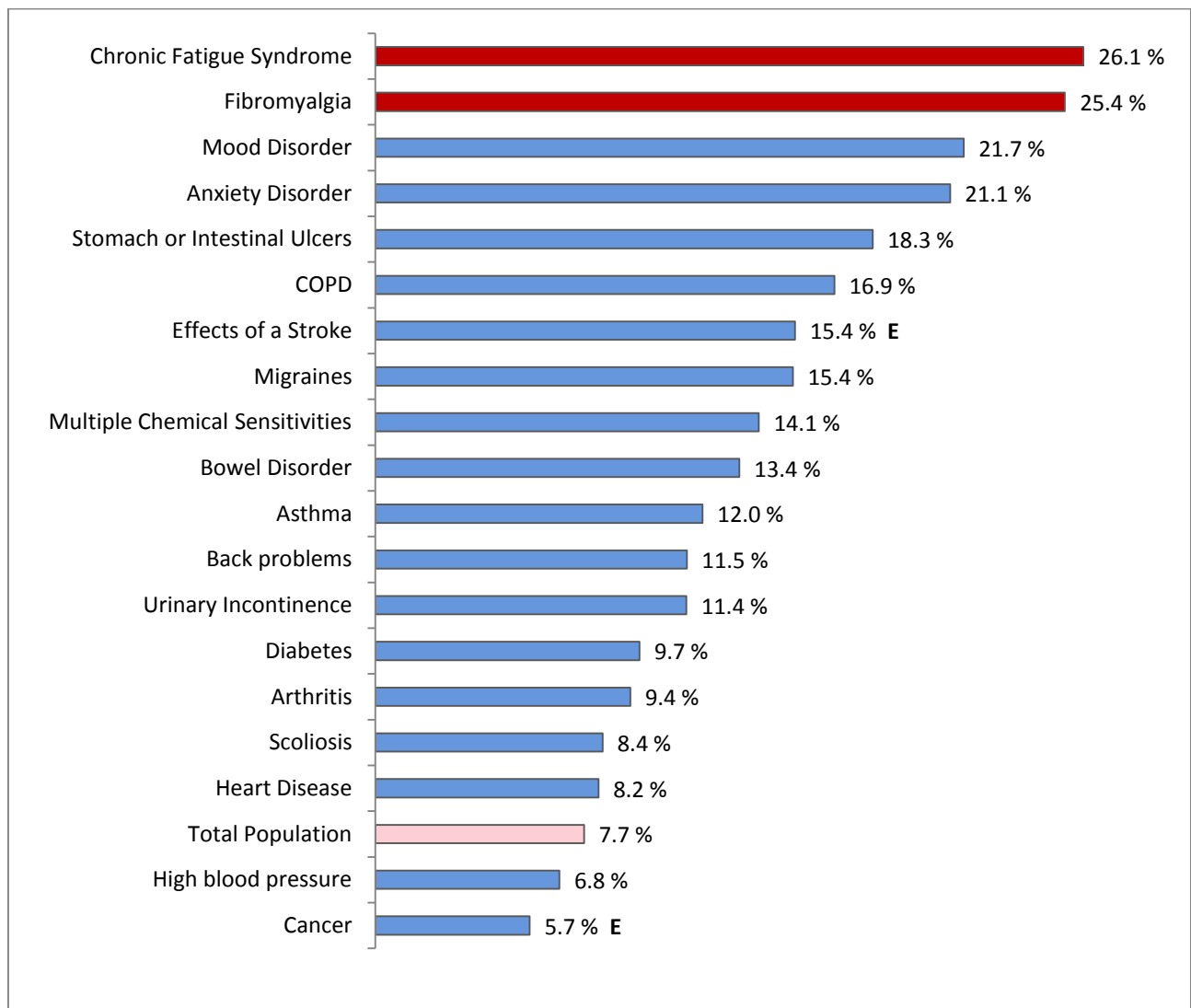


Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File
 COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)
 Arthritis = ages 15+; COPD = ages 35+; Urinary Incontinence = ages 25+

These findings show high rates of poverty among people with ME/CFS or Fibromyalgia. People with these conditions may be unable to work full-time or may be out of the work force entirely. The situation can continue for extended periods of time. People who cannot work often encounter difficult qualifying for income support. For the people who do qualify, the payments can be very low. Poverty among people with these conditions hinders their ability to recover from illness.

FOOD INSECURITY

Canadians Aged 12 and Older Reporting Moderate or Severe Household Food Insecurity According to their Chronic Health Condition, 2014



Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File

COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)

Arthritis = ages 15+; COPD = ages 35+; Urinary Incontinence = ages 25+

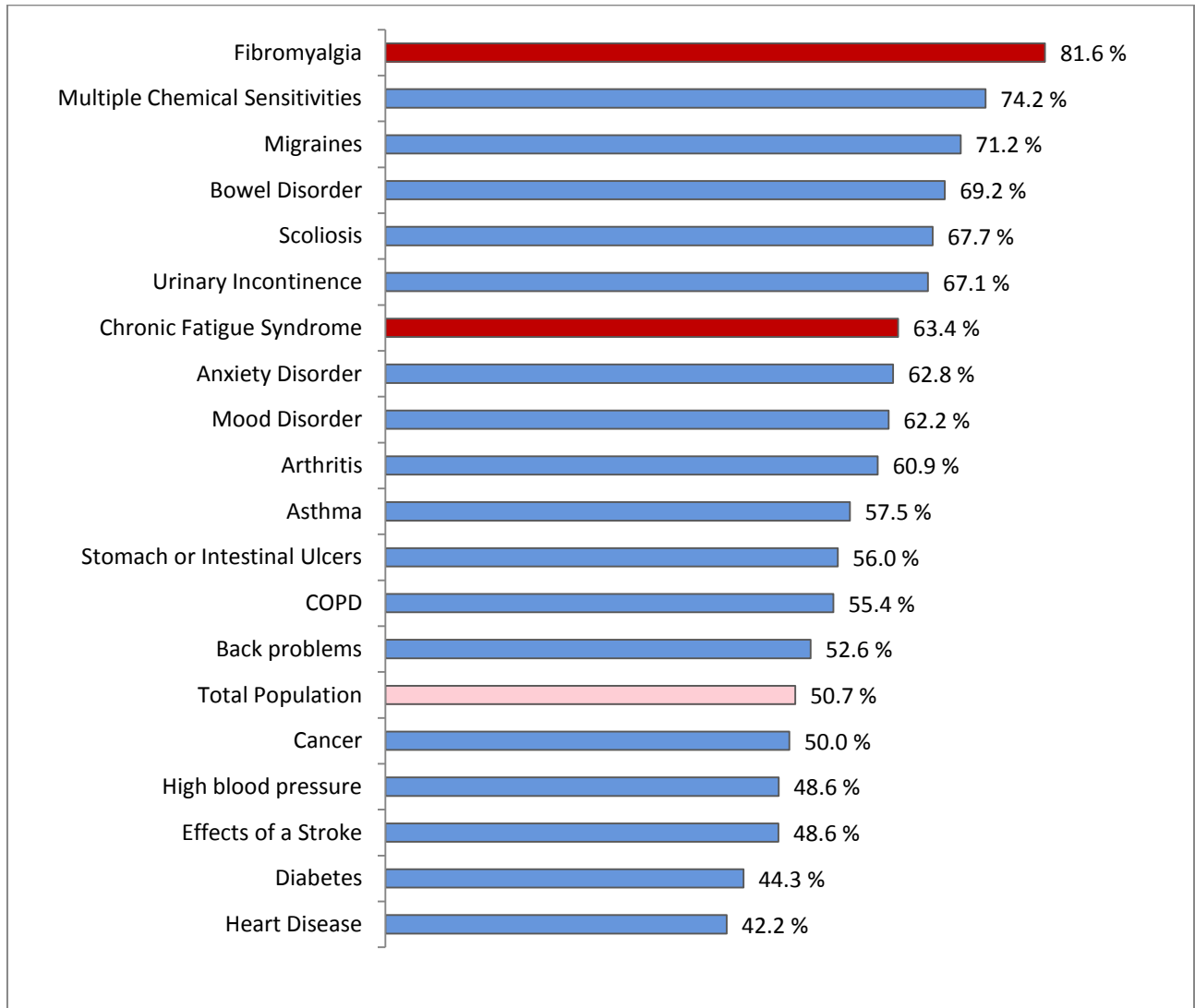
E = Use with caution (Coefficient of Variation between 16.6% and 33.3%)

Respondents from Alberta, Saskatchewan, Ontario, Quebec, New Brunswick, Nova Scotia, Prince Edward Island

Food insecurity is a very concrete indicator of marginalization or deprivation in society. One quarter of people with a diagnosis of ME/CFS or Fibromyalgia are experiencing household food insecurity. There are many reasons for food insecurity including reduced financial resources and limited energy for shopping and food preparation. Food insecurity may be complicated by food intolerances and expensive costs of alternative ingredients. Without adequate access to healthy food, the ability to recover from illness is greatly impacted.

GENDER

Percentage of each Chronic Health Condition that is Female

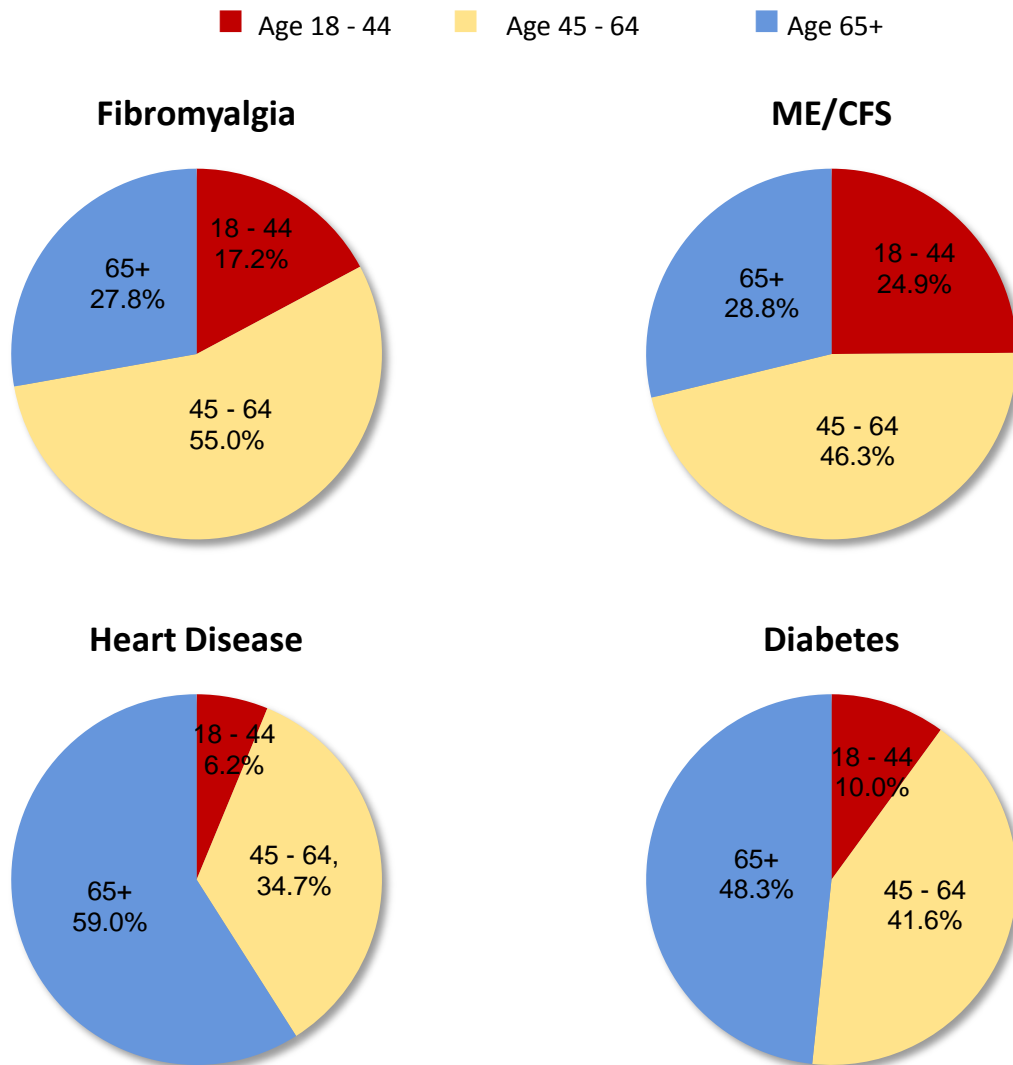


Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File
 COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)
 Arthritis = ages 15+; COPD = ages 35+; Urinary Incontinence = ages 25+

Over 80% of people with Fibromyalgia are female and this proportion is greater than that for any other chronic condition. For people with ME/CFS, about two-thirds are female. The reasons why these illnesses occur more commonly among women are not fully understood. Aside from biologic reasons, it is possible that women are more likely to be diagnosed or are more willing to report their diagnoses.

AGE

Age Distribution for Selected Chronic Health Conditions



Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File

Many chronic illnesses are found largely in seniors (age 65+). More than 50% of people reporting a diagnosis of Heart Disease, Stroke, Urinary Incontinence or Cancer were seniors. Between 45% and 50% of people reporting a diagnosis of Diabetes, High blood pressure, COPD or Arthritis were seniors. In contrast, over 70% of people reporting a diagnosis of ME/CFS or Fibromyalgia were of working age. Contracting a major illness when of working age has a major impact on people's ability to participate in family, work and community activities and to save for retirement. It is also harder for pre-seniors to qualify for benefits like income support or home care than it is for seniors to do so.

METHODOLOGY/TECHNICAL NOTES

The data come from the Canadian Community Health Survey (CCHS), a population-based cross-sectional survey that provides important information about health issues in Canada. The target population is Canadians aged 12 and older but excludes people living on Indian Reserves, residents of institutions, full-time members of the Canadian Forces and residents in certain remote regions. In 2014, the target population included 30,167,000 Canadians, over 97% of Canadians aged 12 and older.

Canadians who participated in the survey were interviewed either in person or on the telephone. They are asked about having “long-term conditions”, (defined as those which are expected to last or have already lasted 6 months or more) that have been diagnosed by a health professional. Participants are asked about multiple chronic conditions and may answer “Yes” to having any number of chronic conditions; therefore, the same individual may be included in more than one chronic condition group.

The CCHS asks about “Chronic Fatigue Syndrome”. In this report it is referred to as Myalgic Encephalomyelitis / Chronic Fatigue Syndrome or ME/CFS.

Information about each of the chronic conditions is asked from all Canadians aged 12 and older with the exception of Arthritis (ages 14+), Chronic Obstructive Pulmonary Disease (ages 35+), and Urinary Incontinence (ages 25+). For analysis with the Public Use Microdata File (see below), data on Arthritis is only available for those aged 15+. Information about each of the measures is asked from all Canadians aged 12 and older with two exceptions. Unmet Home Care Needs is asked from those aged 18 and older. Permanently Unable to Work is asked from those aged 15 to 74, but the graph uses the range 18-64 because employment social programs are often based on this age group.

The questions that form the basis of each of the graphs were asked in all provinces and territories with two exceptions: Unmet Home Care Needs and Food Insecurity. The footnotes to these two graphs show their coverage.

The data in the graphs are based on a sample of Canadians. A coefficient of variation is a measure of the magnitude of sampling variation. Results with large coefficients of variation, determined using guidelines established by Statistics Canada, are marked with an “E”. These results should be interpreted with caution.

With the exception of Unmet Home Care Needs, the data presented are extracted from the 2014 Public Use Microdata File provided by Statistics Canada. Information on Unmet Home Care Needs was provided by Statistics Canada in a custom tabulation generated from the CCHS Master File.

This analysis is based on the Statistics Canada Canadian Community Health Survey Public Use Microdata File, 2014. All computations, use and interpretation of these data are entirely that of the National ME/FM Action Network.

*Statistics from the 2005 Canadian Community Health Survey are available at:
http://mefmaction.com/images/stories/quest_newsletters/Quest80springsummer2009.pdf*

*Statistics from the 2010 Canadian Community Health Survey are available at:
http://meao.ca/files/Quantitative_Data_Report.pdf*

