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ME / FM
ACTION NETWORK

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SPECIAL EDITION

This entire issue of Quest is dedicated to the report: "Profile and Impact of 23 Chronic Conditions in the 2005 Canadian Community Health Survey".

The author is our President, Margaret Parlor. She was talking to someone who mentioned that he sometimes did not have enough money to buy food. Having worked for many years as a statistician, Margaret wondered what the Canadian Community Health Survey, a major Statistics Canada survey, said about food security for Canadians with ME/CFS and FMS. The data indeed showed that quite a number of people were going hungry. She then asked what the survey said about other health and social issues facing Canadians. To help give perspective to these issues, she asked how people with other chronic conditions were affected. This report is a result of her investigations.

We encourage you to share this newsletter with family and friends, as well as politicians and health officials who can help to address the issues raised in this report. The information will be posted at www.mefmaction.net, and additional copies of the newsletter can be purchased from the Network.

Sincerely,
Lydia E. Neilson, M.S.M.
Chief Executive Officer.



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Profile and Impact of 23 Chronic Conditions In the 2005 Canadian Community Health Survey

The Canadian Community Health Survey was designed by Canadian health authorities and conducted by Statistics Canada. The CCHS provides valuable information about the profile and impact of chronic health conditions. This is information that can be used to guide priority setting and resource allocation. You can learn more about the survey at the end of this document.

Attached are 8 factsheets from CCHS 2005 that show how Canadians with 23 chronic conditions fared on issues of impairment, socio-economic disadvantage and health service delivery relative to each other and to the national average. In particular, the factsheets show the percent of people with each condition who reported:

- unmet medical care needs
- unmet home care needs
- food insecurity
- very weak sense of belonging to the community
- needing help with tasks
- experiencing difficulty in social situations
- being permanently unable to work
- personal income under \$15,000

Also included are factsheets showing the prevalence of the various chronic conditions, along with the gender and age distribution of each of the cohorts. The factsheets present the data in new ways which should provoke discussion on a wide range of issues and encourage further investigation in many areas.

The factsheets convey important information about all 23 chronic conditions, but we ask you to look closely at the statistics for Myalgic Encephalomyelitis / Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivities. According to CCHS, more than a million Canadians, predominately female and middle aged, had a diagnosis of one or more of these illnesses. All three conditions reported high levels of impairment, socio-economic disadvantage, and unmet health delivery needs.

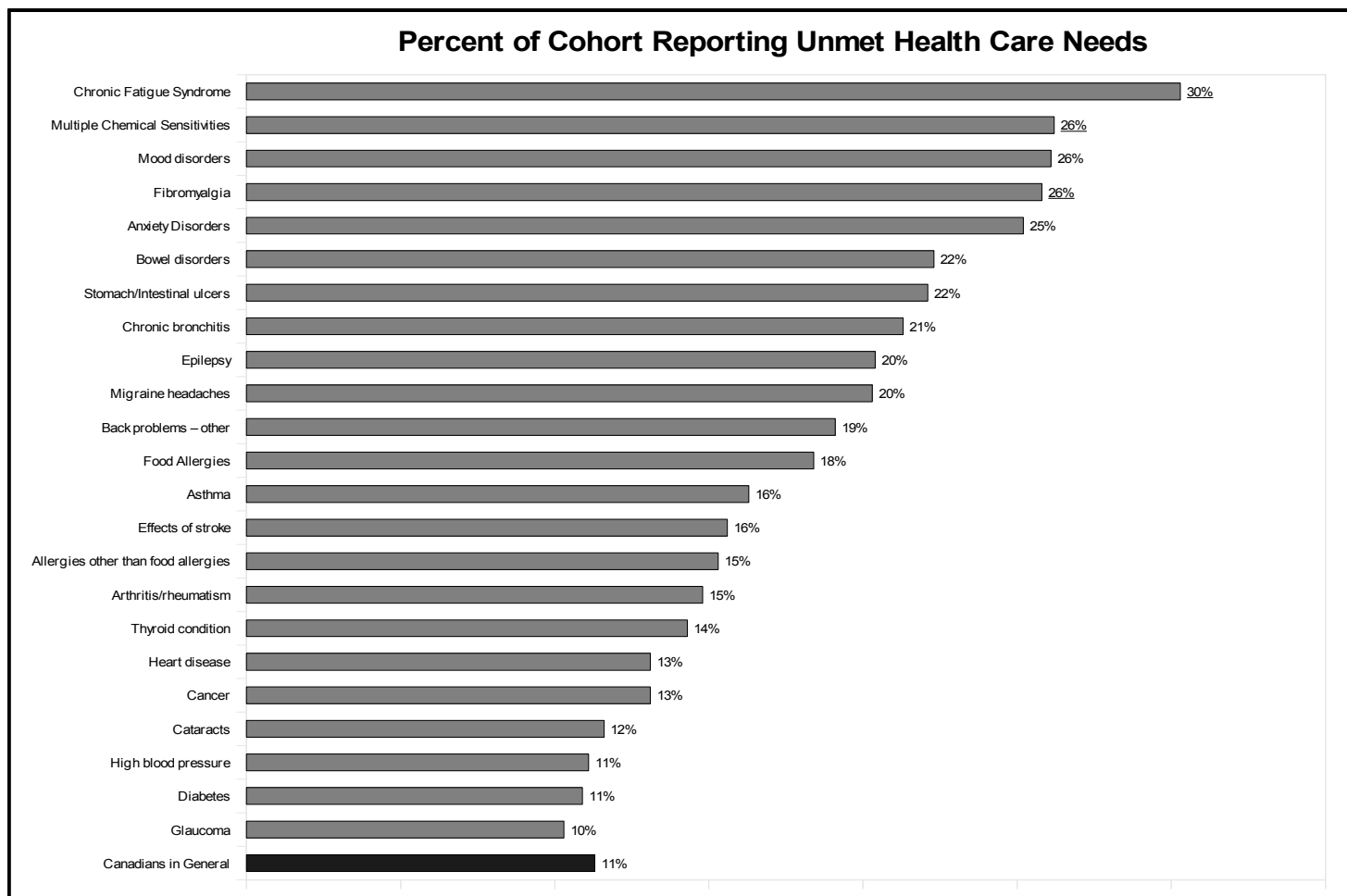
The National ME/FM Action Network is a Canadian registered charity established in 1993 and dedicated to helping people who suffer from Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and/or Fibromyalgia through support, advocacy, education and research. The Network works closely with organizations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



Prevalence of Unmet Health Care Needs For 23 Chronic Health Condition Cohorts

Source: Canadian Community Health Survey 2005

Question: During the past 12 months, was there ever a time when you felt you needed health care but you didn't receive it? (Variable HCUE_06. Responses coded don't know, refusal and not stated have been excluded from this chart.)



People with Chronic Fatigue Syndrome, Fibromyalgia and/or Multiple Chemical Sensitivities often have difficulty finding health professionals to diagnose these illnesses and to provide care, leading to poorer health outcomes and quality of life. Additionally, with inadequate medical support, patients may not receive the accommodations and social supports they need. The health system has achieved lower levels of unmet health care needs for other serious chronic conditions. It is time to work toward reducing the levels of unmet needs experienced by Canadians with Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivities.

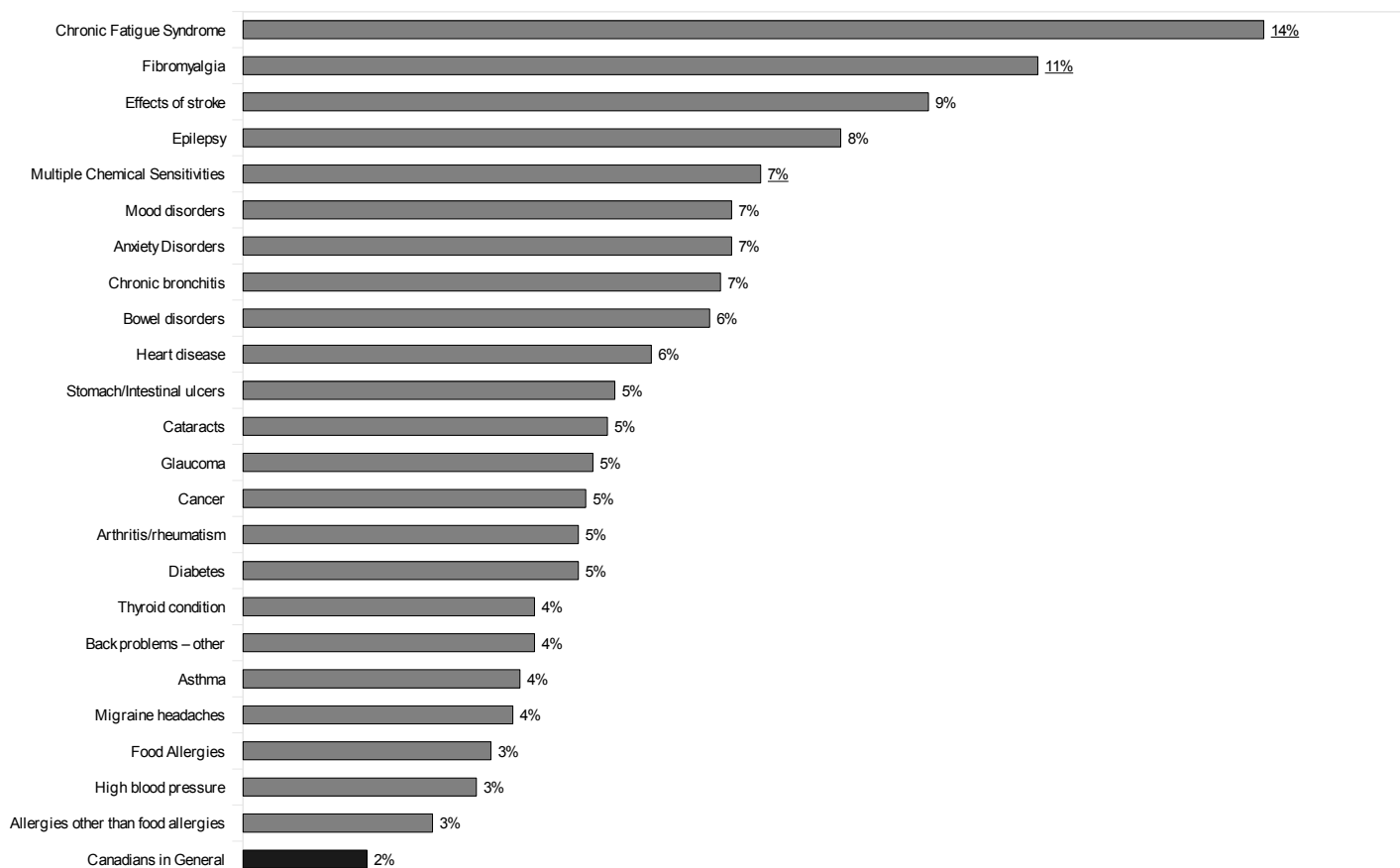


Prevalence of Unmet Home Care Needs For 23 Chronic Health Condition Cohorts

Source: Canadian Community Health Survey 2005

Question: During the past 12 months, was there ever a time when you felt that you needed home care services but you didn't receive them? (Age 18+ Variable HMCE_14: Responses coded not applicable, don't know, refusal and not stated have been excluded from this chart)

Percent of Cohort Reporting Unmet Home Care Needs



While 4% of Canadians reported a diagnosis of Chronic Fatigue Syndrome, Fibromyalgia and/or Multiple Chemical Sensitivities, they accounted for 23% of Canadians with unmet home care needs. Home care programs need to be reviewed to ensure that Canadians with these conditions receive service on an equitable basis.

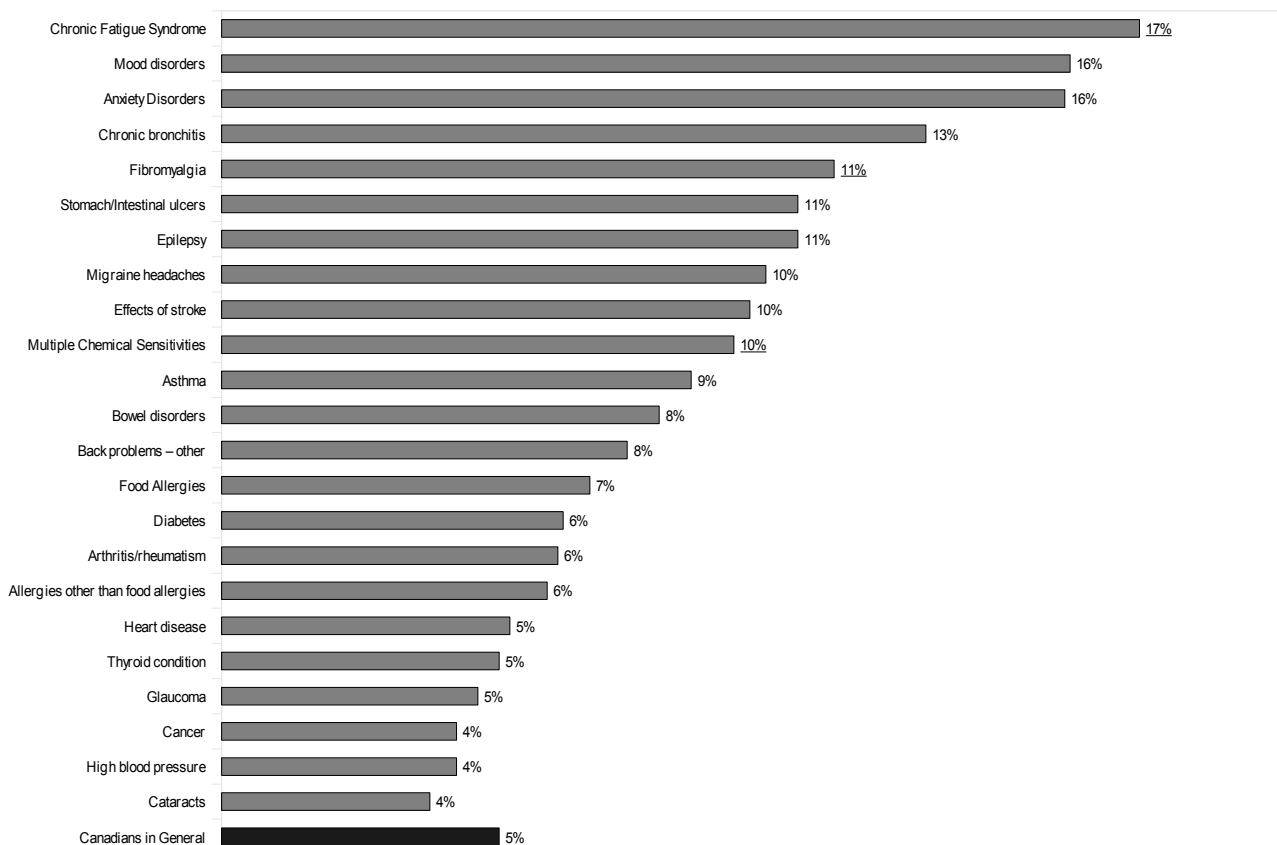


Prevalence of Food Insecurity For 23 Chronic Health Condition Cohorts

Source: Canadian Community Health Survey 2005

Respondents were asked a series of questions about their food security – having consistent access to sufficient nutritious food. Using this information, Statistics Canada determined whether the respondent was food secure or food insecure. (Variable FSCEDHFS: Responses coded not stated and not applicable have been excluded when calculating this chart.)

Percent of Cohort Found to be Food Insecure



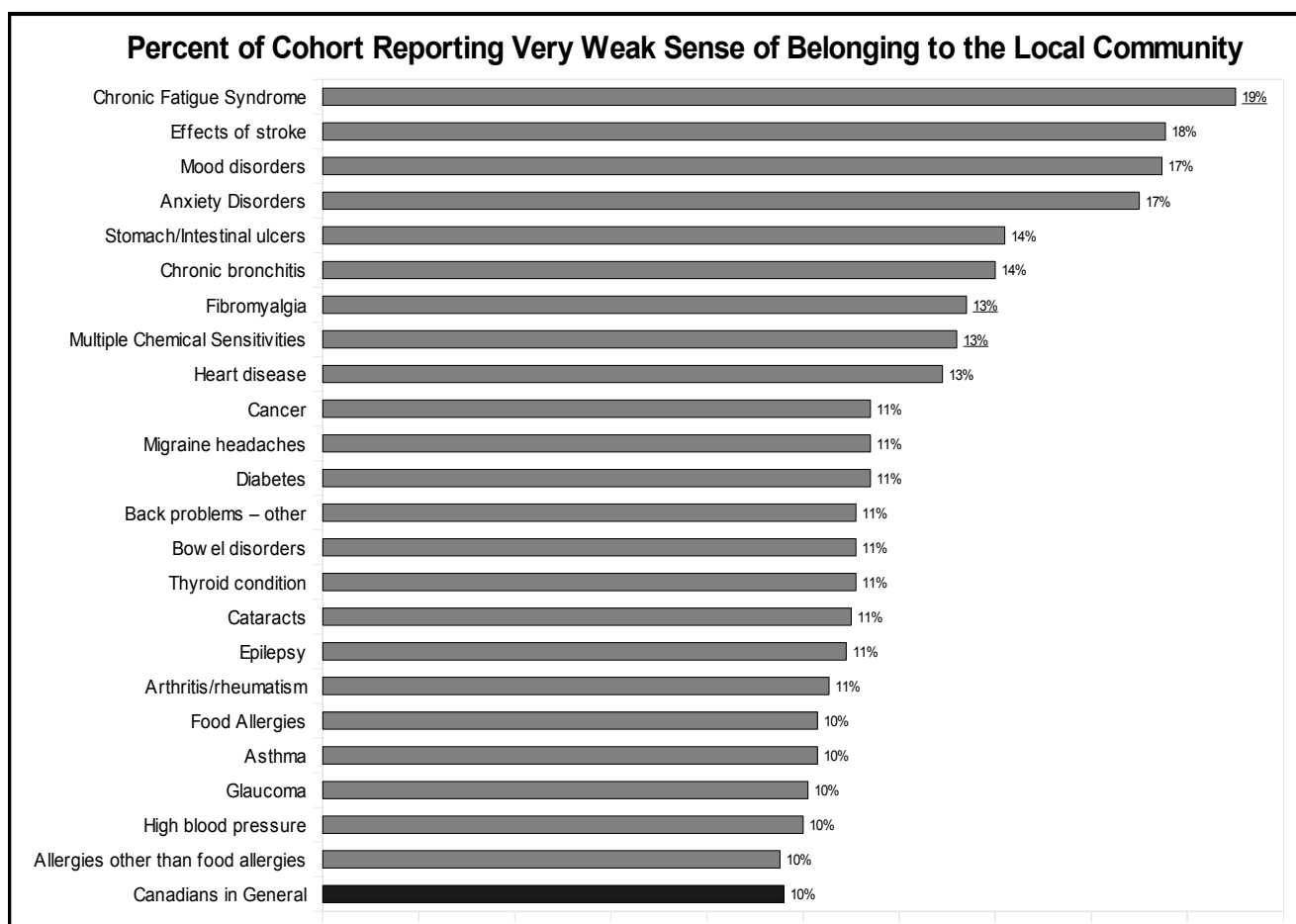
18% of Canadians who reported that they often did not have enough to eat also reported a diagnosis of Chronic Fatigue Syndrome, Fibromyalgia and/or Multiple Chemical Sensitivities. There are many reasons for food insecurity including reduced financial resources, limited energy for shopping and food preparation, and the inability to tolerate certain foods. Research is needed to better understand the metabolic aspects of these illnesses. Food security policies need to be reviewed to take these illnesses into greater account.



Prevalence of Very Weak Sense of Community Belonging For 23 Chronic Health Condition Cohorts

Source: Canadian Community Health Survey 2005

Question: How would you describe your sense of belonging to your local community? Would you say it is very strong? Somewhat strong? Somewhat weak? Very weak? (Variable GENE_10: Responses coded refusal and not stated have been excluded from this chart.)



Many people with Chronic Fatigue Syndrome, Fibromyalgia and/or Multiple Chemical Sensitivities are bedridden, housebound, or able to go out only on a limited basis. The symptoms may fluctuate, making it difficult to plan activities. The sounds, smells and lights of certain environments may provoke symptoms. Community members may not be understanding of or sympathetic to these limitations. Ways have to be found to reach out to these people and give them a stronger sense of belonging.

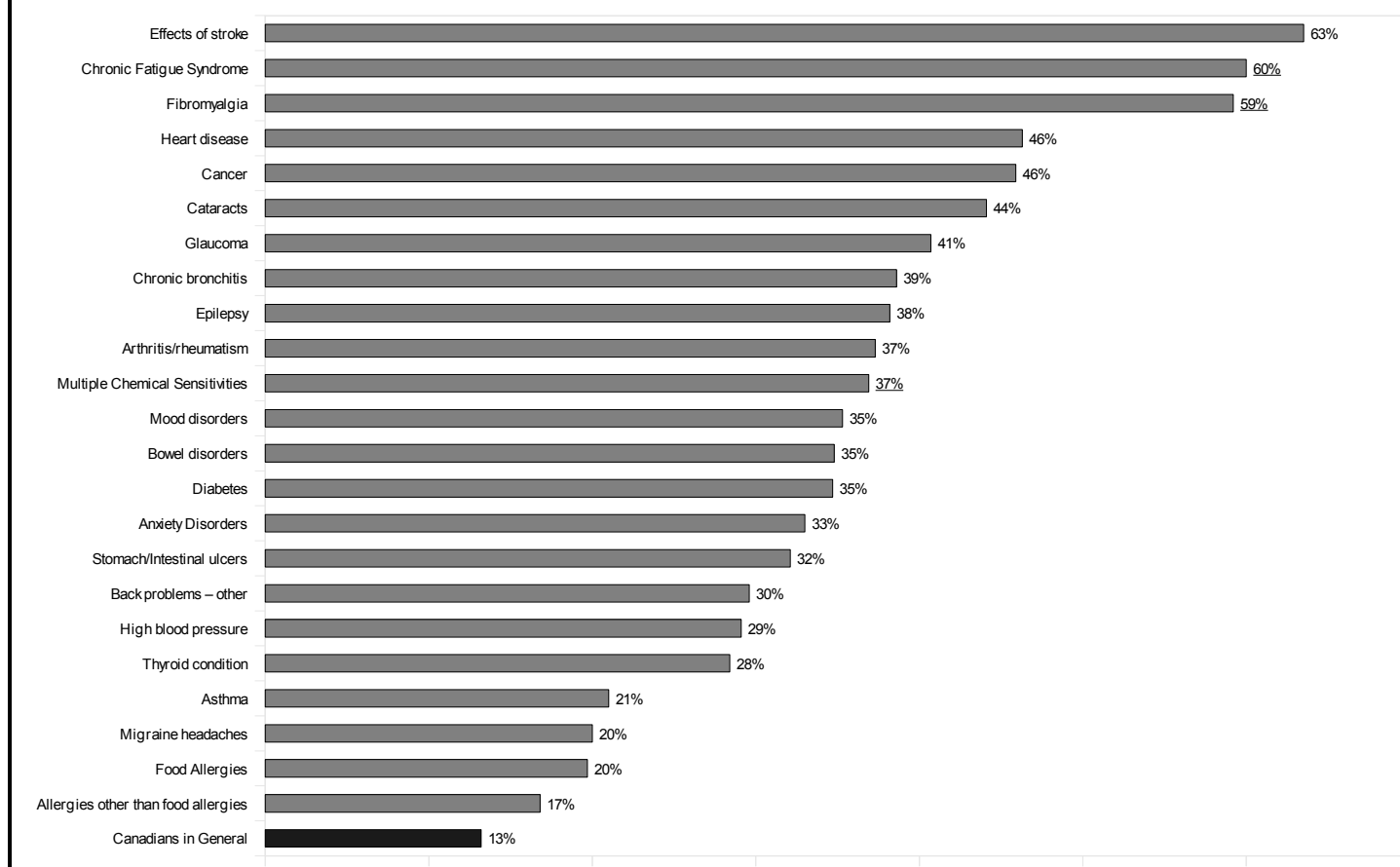


Needing Help For Tasks For 23 Chronic Health Condition Cohorts

Source: Canadian Community Health Survey 2005

Question: Because of your physical condition, mental condition, or health problem, do you need the help of another person with the following: preparing meals? getting to appointments and running errands such as shopping for groceries? doing everyday housework? doing heavy household chores such as spring cleaning or yard work? personal care such as washing, dressing, eating or taking medication? moving about inside the house? looking after your personal finances such as bank transactions or paying bills? (VariableRACEF6R: Responses coded not stated have been excluded from this chart.)

Percent of Cohort Needing Help with Tasks



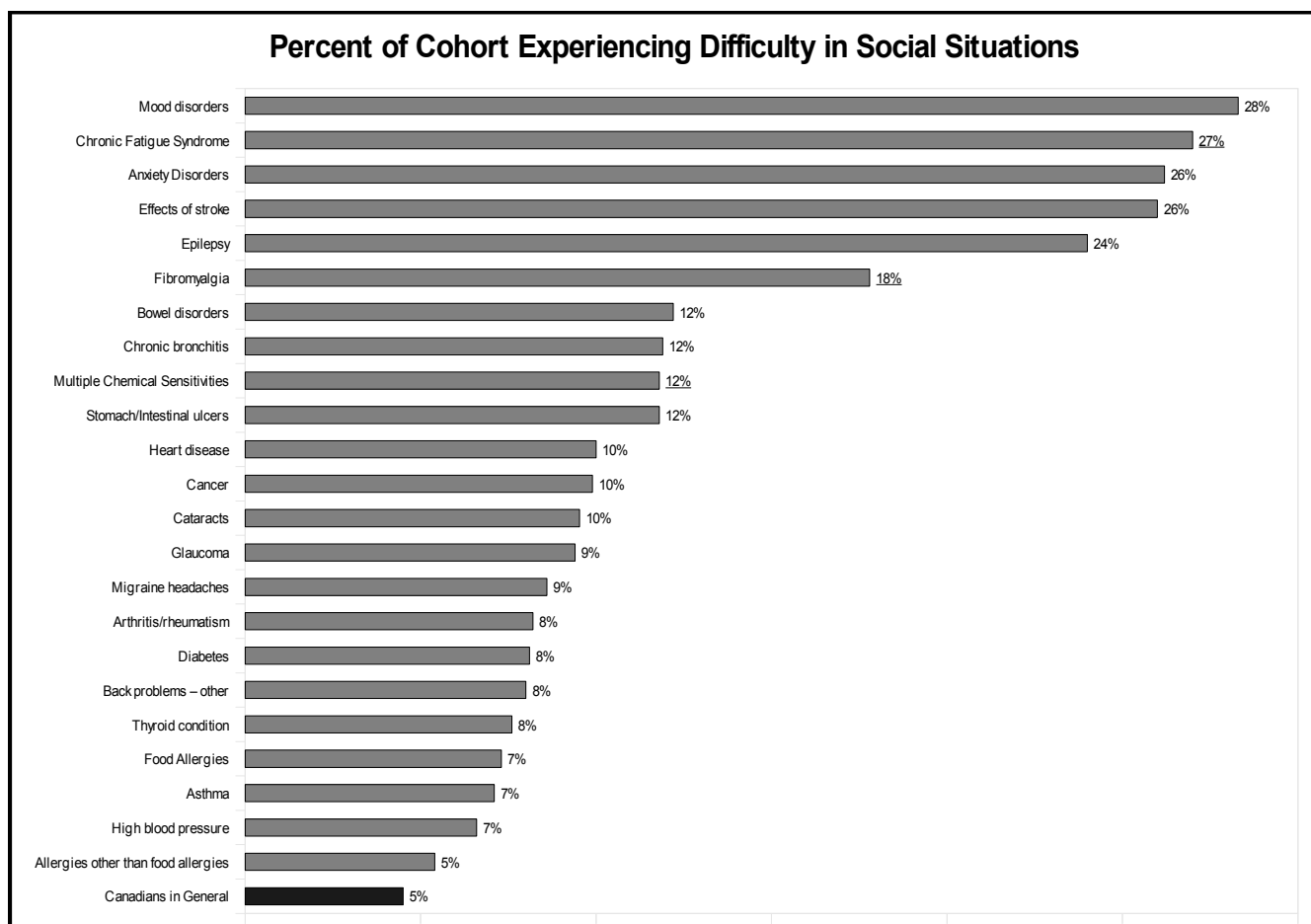
The percentage of persons with Chronic Fatigue Syndrome and Fibromyalgia needing help with tasks is at levels very similar to people who have suffered strokes. Exhaustion, physical pain and mental confusion may all contribute to this difficulty. Needing help with activities is common among the elderly, yet people reporting a diagnosis of Chronic Fatigue Syndrome or Fibromyalgia are generally much younger. This points to a premature loss of independence and self-reliance.



Difficulty in Social Situations For 23 Chronic Health Condition Cohorts

Source: Canadian Community Health Survey 2005

Question: Because of your physical condition or mental condition or health problem, do you have difficulty:
Making new friends or maintaining friendships? Dealing with people you do not know well?
Starting and maintaining a conversation? (Variable RACEF7: Responses coded not stated have been excluded from this chart.)



This chart shows that Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivities have a social impact along with their physical impact. For all three illnesses, people spoke especially of the difficulty around making new friends and maintaining friendships.

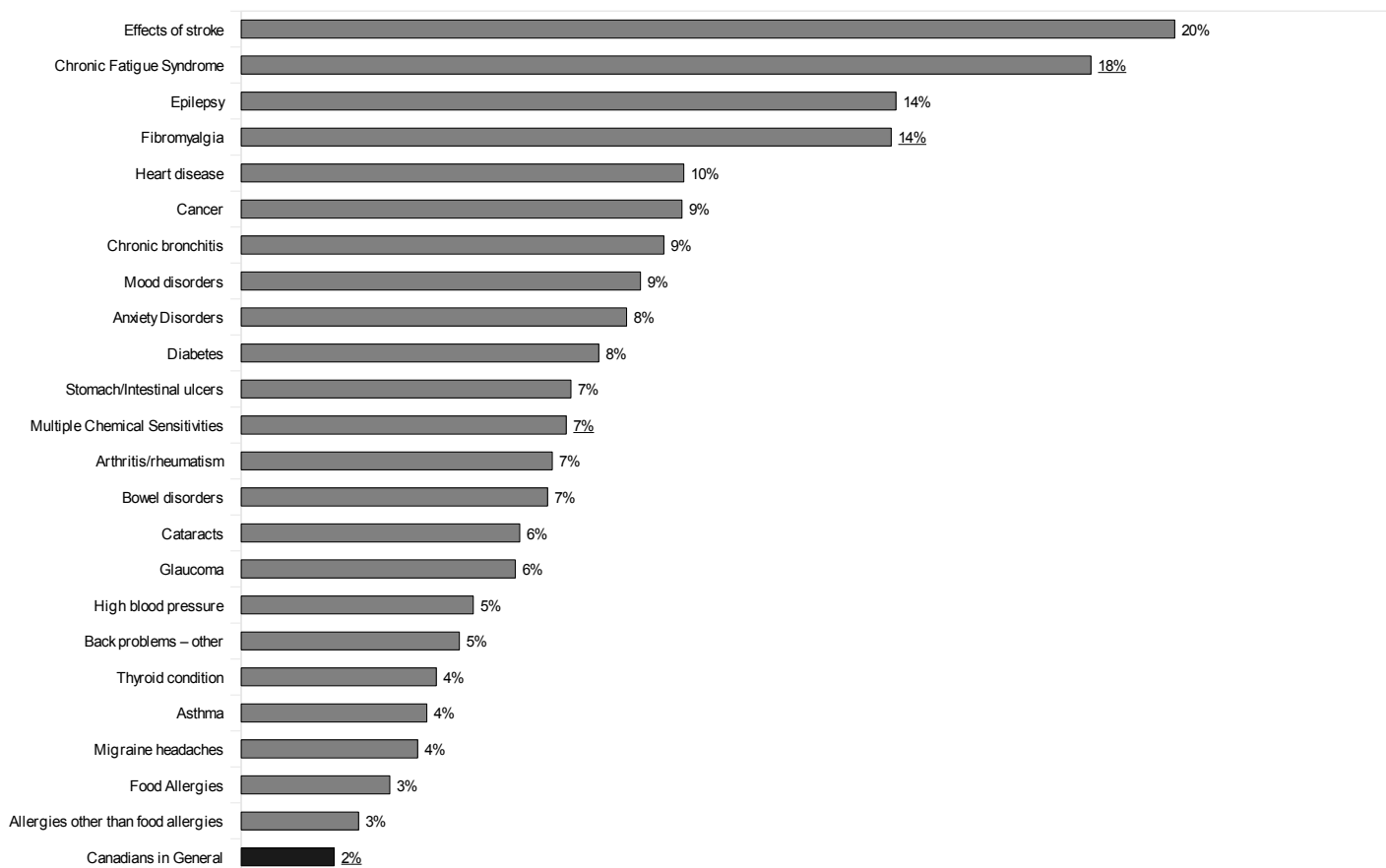


Permanently Unable to Work **For 23 Chronic Health Condition Cohorts**

Source: Canadian Community Health Survey 2005

Question: Last week, did you work at a job or business? Please include part-time jobs, seasonal work, contract work, self-employment, baby-sitting, and any other paid work, regardless of the number of hours worked. Answers: Yes, No, Permanently unable to work. Ages 15-74 only. (Variable LBSEDWSS: Responses coded not applicable or not stated have been excluded from this chart.)

Percent of Cohort Reporting “Permanently Unable to Work”



High levels for this variable suggest a high degree of impairment but also a lack of accommodation of the impairment in the workplace. Part-time work, flexibility around hours of work and home-based employment would allow some people with mild or moderate Chronic Fatigue Syndrome, Fibromyalgia and/or Multiple Chemical Sensitivities to continue to participate in the work force. Having said that, it is critically important that people with these illnesses, their employers and their co-workers understand that there can be serious health consequences if they exceed their health limits.

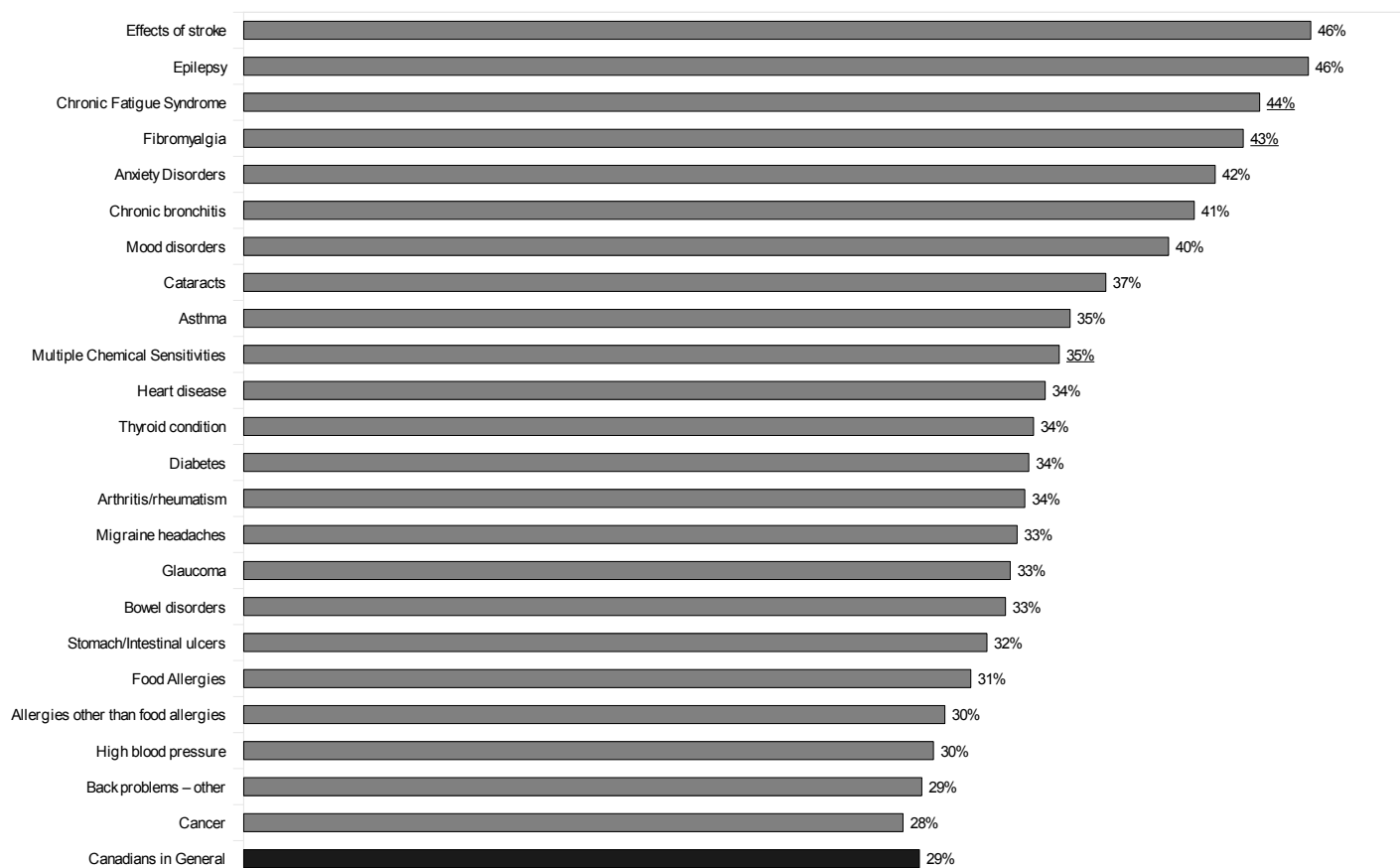


Personal Income Under \$15,000 For 23 Chronic Health Condition Cohorts

Source: Canadian Community Health Survey 2005

Question: What is your best estimate of your total income, before taxes and other deductions, from all sources over the past 12 months? (Age 15+ Variable INCEGPER: Responses coded not stated or not applicable have been excluded from this chart. People with no income are considered to have income under \$15,000.)

Percent of Cohort Reporting Personal Income under \$15k



Financial security is a serious problem for people with Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivities. They may be unable to work full time or they may be out of the work force entirely. This situation can continue for extended periods of time. Those who cannot work often encounter difficulty qualifying for income support.



Prevalence of Chronic Health Conditions

Source: Canadian Community Health Survey 2005

Question: "Now I'd like to ask you about certain chronic health conditions which you may have. We are interested in long term conditions, which are expected to last or have already lasted 6 months or more and that have been diagnosed by a health professional. Do you have"

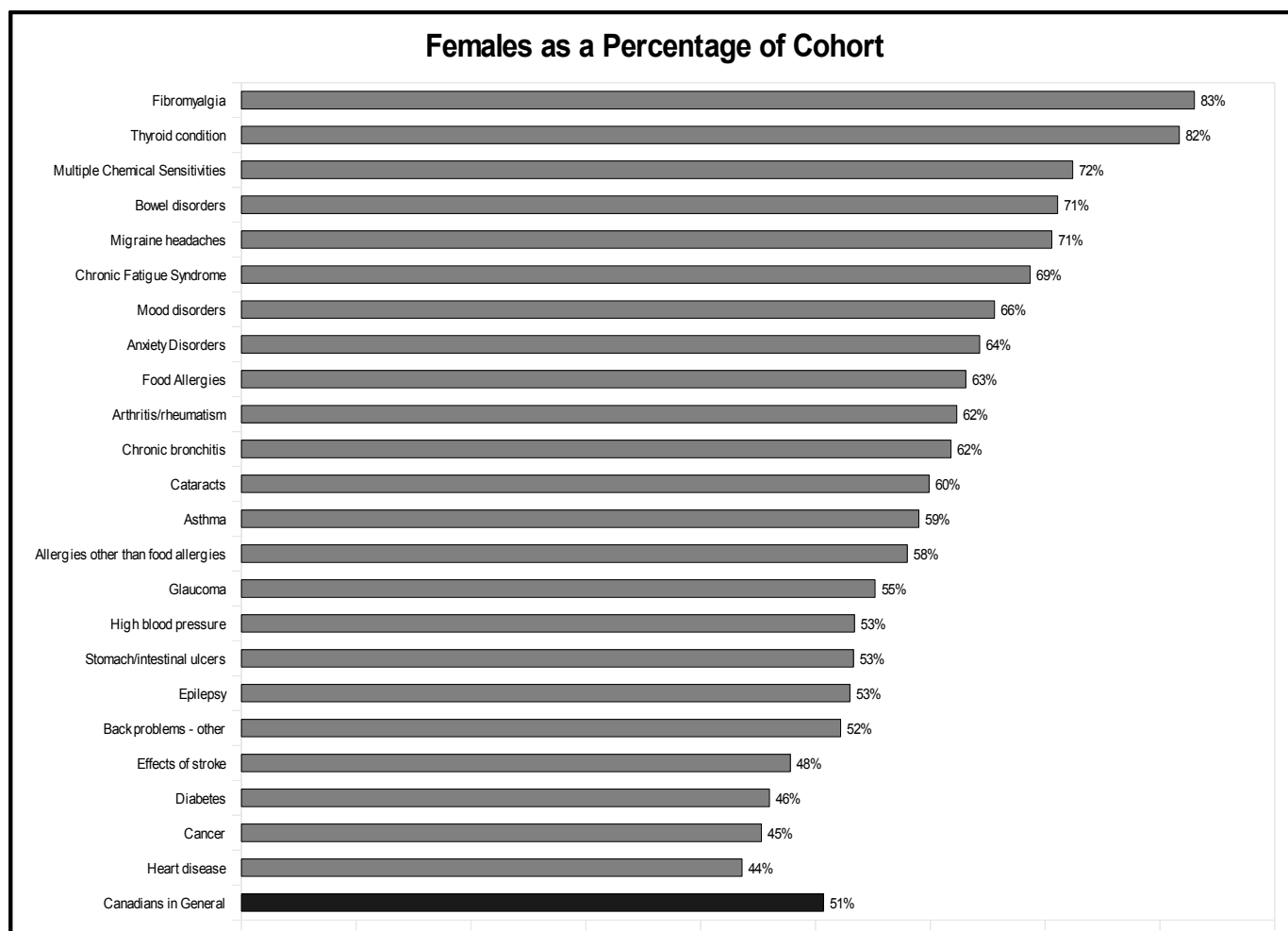
Cohort	Number reporting chronic health condition	% of Target Population
Target Population	27,126,165	
Allergies other than food allergies	7,221,920	26.6%
Other Back problems	5,089,655	18.8%
Arthritis/rheumatism	4,441,851	16.4%
High blood pressure	4,051,794	14.9%
Migraine headaches	2,860,623	10.5%
Asthma	2,249,228	8.3%
Food Allergies	1,964,398	7.2%
Thyroid condition	1,515,994	5.6%
Mood disorders	1,514,253	5.6%
Diabetes	1,324,874	4.9%
Heart disease	1,288,009	4.7%
Anxiety disorders	1,186,549	4.4%
Cataracts	1,143,487	4.2%
Bowel disorders	1,047,243	3.9%
Stomach/Intestinal ulcers	846,823	3.1%
Bronchitis	675,096	2.5%
Multiple Chemical Sensitivities	598,585	2.2%
Glaucoma	407,390	1.5%
Fibromyalgia	389,782	1.4%
Cancer	370,763	1.4%
Chronic Fatigue Syndrome	333,816	1.2%
Effects of stroke	297,547	1.1%
Epilepsy	159,759	0.6%

Altogether 1,135,225 Canadians (4.2% of the target population) reported a diagnosis of Chronic Fatigue Syndrome, Fibromyalgia and/or Multiple Chemical Sensitivities. This is equivalent to the entire population of Calgary, Edmonton, Ottawa-Gatineau or the province of Manitoba. Diagnostic criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia, have been developed by consensus panels established under Health Canada guidelines and are available at www.mefmaction.net. Use of these criteria would ensure that these illnesses are diagnosed on a consistent basis across the country.



Gender Profile For 23 Chronic Health Condition Cohorts

Source: Canadian Community Health Survey 2005



Studies have generally found Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivities to be more common in women than men, though the reasons are not fully understood. There may also be a greater tendency for health professionals to diagnose women with these illnesses, and a greater willingness of women to report the diagnoses.



Age Distribution For 23 Chronic Health Condition Cohorts

Source: Canadian Community Health Survey 2005

Percentage of cohort in each age range (sorted by percentage age 65+)

Target Population	Age 12-24 21	Age 25-44 34	Age 45-64 31	Age 65+ 14
Migraine headaches	19	43	32	6
Anxiety Disorders	17	37	35	11
Mood disorders	14	37	38	11
Allergies other than food allergies	21	36	31	12
Epilepsy	18	35	34	12
Asthma	28	33	26	13
Food Allergies	20	35	32	13
Other back problems	10	33	40	18
Multiple Chemical Sensitivities	8	28	46	19
Fibromyalgia	2	22	56	20
Bowel disorders	8	34	38	21
Chronic Fatigue Syndrome	5	27	47	21
Stomach/Intestinal ulcers	8	32	39	22
Bronchitis	11	26	35	28
Thyroid condition	3	23	42	32
Arthritis/rheumatism	2	14	44	41
High blood pressure	1	11	45	43
Diabetes	2	11	43	43
Cancer	1	9	38	52
Heart disease	2	7	33	58
Effects of stroke	2	7	32	58
Glaucoma	0	6	30	63
Cataracts	1	3	21	75

Most people reporting a diagnosis of Chronic Fatigue Syndrome, Fibromyalgia and/or Multiple Chemical Sensitivities were between the ages of 25 and 64. Studies have generally found a higher prevalence in this age group. However, many people report that they noticed symptoms long before they received a diagnosis, suggesting that cases, or at least warning signals, are often missed in younger people. Older people may not be diagnosed because symptoms such as reduced activity levels, mental confusion and pain may be attributed to aging.



Profile and Impact of 23 Chronic Conditions In the 2005 Canadian Community Health Survey

The Canadian Community Health Survey (CCHS) is an important source of information about health issues in Canada. Statistics Canada released survey results for 2005 in database format on a “Public Use Micro-data File”. Data have been extracted from this file and presented in factsheet format.

The target population of CCHS 2005 was Canadians age 12 and up, with several exclusions:

- persons living on Indian Reserves
- residents of institutions
- full time members of Canadian Armed Forces
- residents of certain remote regions.

Overall, there were 27,126,165 Canadians in the target population. This is about 98% of Canadians age 12 and up.

Statistics Canada interviewed 132,221 Canadians (about 1 in every 200 members of the target population). Respondents were asked a series of health related questions. Their responses were weighted to arrive at estimates for the target population.

Respondents were asked about chronic health conditions as follows:

“Now I'd like to ask you about certain chronic health conditions which you may have. We are interested in long term conditions, which are expected to last or have already lasted 6 months or more and that have been diagnosed by a health professional. Do you have”

Respondents were read a list of chronic health conditions and asked to respond to each one. Possible answers include yes, no, don't know, refuse, and not stated. The chronic condition cohorts in this fact-sheet include only those people who responded “yes” to that condition. The same individual may be included in several chronic condition cohorts.

It is very important to remember that CCHS data is based on self-reporting of diagnosis. The data may or may not reflect how many people actually have the chronic condition. Note also that the statistics are based on sampling and therefore are estimates.

CCHS was not conducted in 2006. It was conducted in 2007, 2008 and 2009 but the questions on Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivities were omitted.

The National ME/FM Action Network represents Canadians with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Fibromyalgia. Margaret Parlor, who is President of the Network, compiled these factsheets. She worked as a data analyst, policy analyst and statistical program manager for many years. Thanks to Linda MacDonald and Maureen MacQuarrie for their help with the analysis.

Network Resources

The following resources can be ordered from the National ME/FM Action Network. Prices include shipping and handling. Cheques should be made payable to the National ME/FM Action Network or you may pay by VISA or MasterCard.

Quest # 80 (copies of the present edition) : \$2.00 NEW

Quest Collections: By popular request, the **National ME/FM Action Network** has published three collections of important articles which have appeared in 'QUEST' newsletters. The articles in each five-year collection have been grouped into sections according to their focus.

Quest Collection I: presently out of print

Quest Collection II (1999 – 2003): \$38.00

Quest Collection III (2004-2008) Will be published shortly – orders accepted now: \$38.00 NEW

TEACH-ME: A Sourcebook for Teachers (Second Edition): \$22.00 *Discount on bulk orders*
With Dr. D. S. Bell, Dr. B. M. Carruthers and the TEACH-ME Task Force (teachers with ME/CFS and/or FMS). This educational resource book will enhance teachers' and parents' understanding of ME/CFS and FMS in young people, and assist educators in developing educational modifications and programs.

TEACH ME: (traduction française): Guide de référence pour l'enseignement aux élèves souffrant d'EM/SFC et/ou de la FM. \$22.00, 120 pp.

The Canada Pension Plan Disability Benefits Guidelines: \$7.00: Guidelines have been designed to assist those disabled by ME/CFS and/or FMS applying for Canada Pension Plan Disability Benefits. It will help you understand the criteria, important items to include and walks you through the various steps of the process.

THE INTERNATIONAL ASSOCIATION FOR CFS/ME: To promote, stimulate and coordinate the exchange of ideas related to CFS/ME and FM research, patient care and treatment.

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Network Notes

IME/FAE Registry Submission

The **National ME/FM Action Network** continues to urge those who have attended an **Independent Medical Examination (IME)**, **Functional Abilities Evaluation (FAE)** or any other form of assessment at the request of an insurance company, Canada Pension Plan (CPP) or Workplace Safety & Insurance Board (WSIB) to fill out our 7-question, confidential, **Independent Medical Examination Registry Submission Form** so that the names of the doctors and healthcare professionals who evaluated you can be put on record. Patients, doctors, lawyers, advocates, support groups wishing to receive a copy or copies of the Form, or to inquire about specific IME doctors, please contact: **National ME/FM Action Network** – Or download the Form from our website at www.mefmaction.net.

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MEMBERSHIP: \$25.00 per year, which includes quarterly newsletters
Payment can be made by CHEQUE, VISA or MASTERCARD.

Do not email credit card information.

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