

## Arthritis Consumer Experts Survey Report on Arthritis and Health Literacy: Part 1

Arthritis Consumer Experts (ACE) is Canada's largest patient led arthritis non-profit organization. ACE is committed to raising awareness about unfairness in arthritis care. From June 1 to 25, 2023, ACE conducted a 40-question national online Survey in English and French to understand health literacy levels of people living with arthritis. People who responded answered questions about their socioeconomic status, ability to understand and use health information, communication with health care providers, ability to use information in decision making, self-care and how they increase health knowledge.

### In this issue of JointHealth<sup>TM</sup> insight

Background	Pg. 2
Who were survey respondents?	Pg. 2
Ability to find, process and use health information	Pg. 3
Ability to use information in decision making	Pg. 3
What does it mean for arthritis care?	Pg. 6

**Click here to download the "Health Literacy in People Living with Arthritis: Part 1" infographic.**

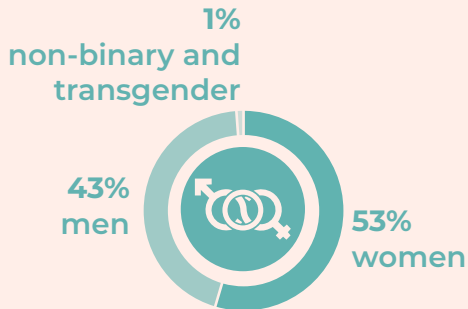
In Part 1 of the analysis, we look closely at results from two groups of Survey responses:

- Women compared to men
- Age groups (over 54 years, 34-53 years, and under 33 years)

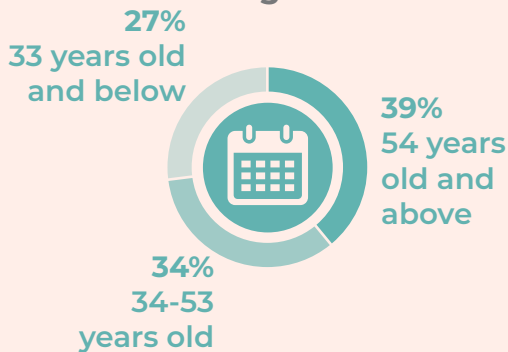


## Who were the Survey respondents?

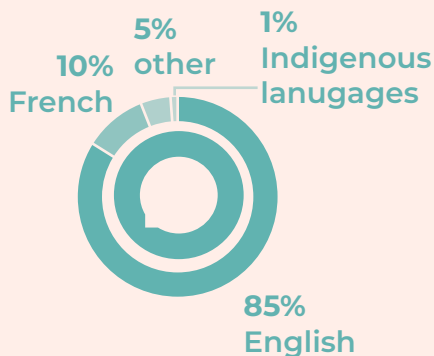
### Gender identity



### Age



### First Language



## Background

Health literacy means being able to find, understand and use basic health information and services to take care of one's daily health needs.<sup>1</sup>

Health literacy includes knowing how to:

- (1) understand medical information
- (2) find health services and resources
- (3) make lifestyle changes to improve overall health
- (4) talk about symptoms with health care providers
- (5) take medications
- (6) self-care for physical, emotional, and mental health
- (7) share health and wellness activities with others
- (8) address health issues in the community and advocate for better health care

People with limited health literacy have challenges understanding and using health information they find unfamiliar, complicated or too technical, which can lead to increased healthcare costs and worse health outcomes.

## Who were the Survey respondents?

A total of 1,148 Survey responses were received. These people will be referred to in this writing as "respondents."

Half of respondents identified as women (53%), while 43% were men. Non-binary and transgender respondents represented approximately 1% of responses. Nearly half of the Indigenous respondents said they were Two-spirited.

Age range was well distributed:

- 448 (39%) were born before 1969 = 54 years and above
- 386 (34%) were born between 1970 to 1989 = 34 to 53 years
- 314 (27%) were born after 1990 = 33 years and below

Most respondents spoke English as their first language (85%), then French (10%), other languages (5%) and Indigenous languages (1%).

For more demographic information including ethnicity, education, income and type of arthritis, please refer to the **Appendix** at the end of this newsletter.

# Survey findings

## Understanding and using health information

Navigating the world of health information can be challenging. Information can come from online content and main stream media sources to advice from family and friends. It's important to understand this information and use it to make the best choices possible and communicate effectively with health care providers to improve health outcomes.

ACE's Survey findings showed that women can find, understand, and use health information about the same as men. But younger respondents under 33 years were better at finding, understanding, and using health information when compared to those 34 years and older.

## Communicating with health care providers

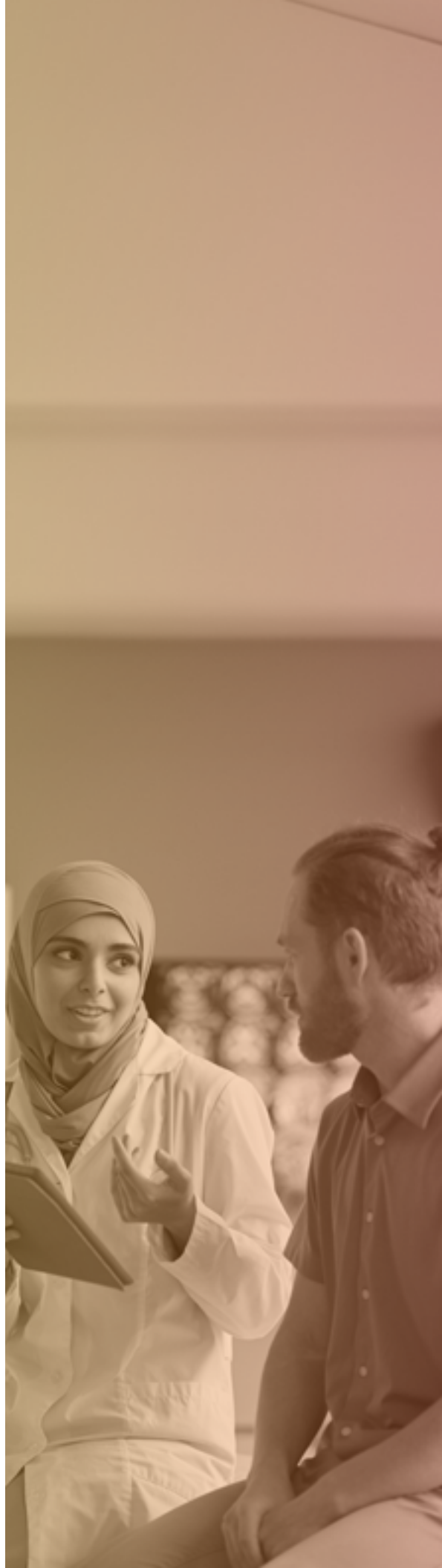
To make arthritis care fair for everyone, it's important that patients and health care providers talk to each other in a clear, respectful, and inclusive way. Compared to respondents who are under 53, people who were 54 and older said that their health care provider explained health issues clearly and listened carefully, but also reported their provider used hard-to-understand words.

## Using information to make better health decisions

Using health information to make choices is very important. It helps people understand their health challenges, pick the best treatments, do beneficial physical activities, and eat healthy foods. ACE asked people to rate their ability to use information to make decisions from 1 (not confident) to 5 (very confident).

Women (when compared to men) were better at understanding why they take medications (56% vs 44%), how to take them (63% vs 52%) and had fewer challenges taking medications as told (38% vs 31%).

Women and men felt about the same about doing physical activities regularly (20% said they were "very confident"). Women reported higher understanding compared to men about the purpose of physical activity (57% vs 46%) and how, where, and when to do it (41% vs 31%).





The biggest difference between women and men was related to diet. Women were better at understanding healthy eating (56% vs 32%), reading food labels (32% vs 19%) and what foods to avoid (24% vs 18%).

People 54 years and older reported better understanding why they take medications, how to take them and had fewer challenges taking them compared to those under 53. This was also true for exercise and eating habits. Older respondents demonstrated better understanding, ability, and confidence to follow healthy behaviours.



[Click to read what respondents told us >>>](#)

## Taking care of yourself

Self-care is an important part of managing arthritis. This can include going to educational workshops and webinars, seeking help from others, and using resources online. Doing these things helps patients learn more about how to manage and take control of their health.

ACE's Survey uncovered interesting trends in self-care habits. More men than women said that they went to workshops or webinars (32% vs 25%) and to support group meetings (36% vs 19%). But more women reported asking for help from other (35% vs 25%).

Respondents 53 years and younger went to workshops and webinars, support group meetings, and used online guides more often compared to respondents over 54.

## What health knowledge or skills do you need the most?

Men said that the most valuable health knowledge or skills were finding health info (20%), finding health programs and services (20%) and learning how to advocate (20%). Women reported the most valuable skill was finding health info (20%), while 27% of women said they were confident in their own knowledge and skills.



- 54 years and older: I am confident in my own knowledge and skills (37%)
- 34 to 53 years: find health programs and services (20%), learn how to advocate (23%)
- 33 years and younger: find health info (21%), find health programs and services (22%), learn how to advocate (26%)

Overall, these findings highlight the importance of creating an environment that supports and encourages self-care skills and acknowledges the diverse needs and preferences of patients.

## Gaining knowledge

Increasing your health knowledge and skills allow patients to learn about new treatments, understand research, and deal with changes in health.

ACE asked people how they want to improve their health literacy and most said they want to learn from a health care provider.

Women respondents more often than men wanted to learn from:

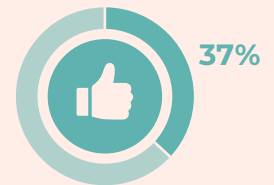
- A health care professional (51% vs 43%)
- Online courses (25% vs 16%)
- I'm confident in my current health knowledge and skills (20% vs 12%)

Men (compared to women) wanted to learn from:

- Online community or support groups (35% vs 22%)
- 1 on 1 counselling (29% vs 22%)
- Other patients (17% vs 13%)

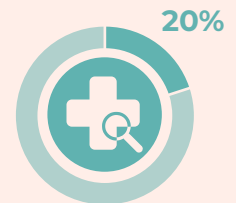
People under 33 wanted to learn from “1 on 1 counselling” and “online community or support groups.” Respondents over 34 years more often said they were “confident in my current health knowledge and skills.”

What health knowledge or skills do you need the most?

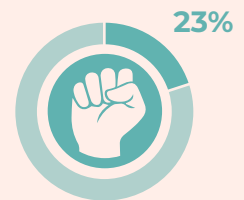


**I am confident in my own knowledge and skills**

35 to 54 years old need knowledge or skills to

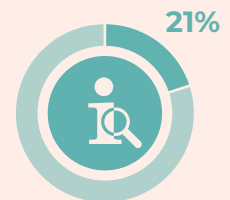


**find health programs and services**

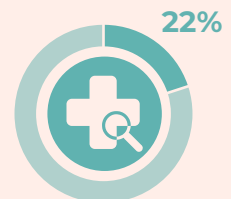


**learn how to advocate**

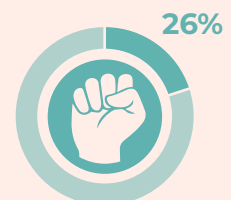
33 years old and younger need knowledge or skills to



**find health info**



**find health programs and services**



**learn how to advocate**



**Click to read what respondents told us >>>**





## What does it mean for arthritis care?

The Arthritis Consumer Experts Health Literacy Survey provides valuable insights into the challenges and needs of individuals living with arthritis. It shows us how health literacy is key to the self-care of arthritis and the various experiences and preferences among people living with arthritis.

Our findings show that men and women have different levels of health literacy. For example, women may have more confidence with medication and eating well, while men may have more confidence knowing how, where, and when to do physical activity.

When looking at the responses from different age categories, respondents 54 and older reported higher health literacy than those under 54, suggesting that knowledge, skills, and confidence increase over time.

One major challenge across all groups was knowing where to access health information. This highlights the need for better ways to find resources for arthritis care. Although we live today in an information-rich society many Canadians experience obstacles and barriers to find, understand and use health information. Eliminating these obstacles and improving the way health services, health care providers and policymakers, and the media communicate, and share health information would offer the best opportunity to achieve a gold standard of health literacy for all people.

The Survey findings also highlight how we can take steps to improve health literacy.

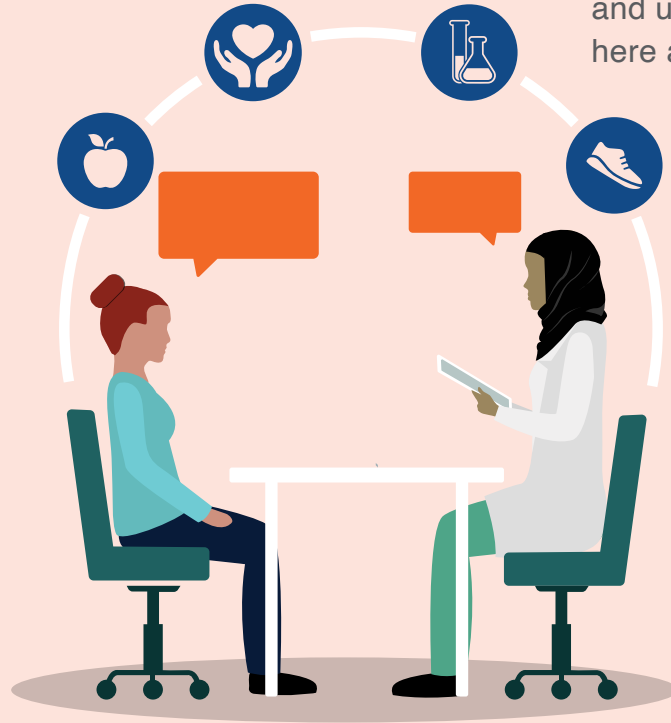
## People living with arthritis

need to develop skills to find, understand, evaluate, communicate, and apply health information to their specific context. Here are some ways how:

**Take an active role** in healthcare decisions – be a participant in health, not a spectator

**Ask questions** and get good information to better understand the disease and how to better manage it – being curious is a good thing

**Ask for support** where and when needed – asking questions is the road to learning



## Health care providers

can help their patients improve their health literacy by giving information in ways that make it easier to understand and use. Based on Survey findings, here are some ways how:

Talk with patients in **clear and simple terms**

**Take medical jargon out** of the conversation with the patient

Show patients in real ways that **you have heard their concerns** and understand them

**Give time for patients to ask questions** and consider using pictures, videos and graphs to help them learn what you need them to know

**Policymakers** can support health literacy by providing culturally relevant and sensitive information and resources to ensure fair access to health care services. Here are some ways how:

Think about ways to **make sure online health information is current**, easy to find, and written at a grade 6 to 8 reading level

Work with the medical education community to **make certain that racial minorities have equal opportunities** to train to be medical doctors

Work with the medical research community to **make certain the voice of racial minorities is represented** and included in health research



## More information sources on health literacy can be found here:

- [Health Literacy in Canada: A Healthy Understanding, 2008](#)
- [A Vision for a Health Literate Canada: Report of the Expert Panel on Health Literacy](#)
- [Public Health Association of BC: An Inter-sectoral Approach for Improving Health Literacy for Canadians, 2012](#)
- [Arthritis At Home 164: Communicating science to patients and ways to recognize pseudoscience](#)

## References

1. Health Literacy in Canada: A Healthy Understanding – Canadian Council on Learning, 2008

## Appendix

Table 1: Sociodemographic information

Progress-Plus Framework	
Place of residence*	
Large urban centre (population of 100,000+)	670
Small-medium sized population centre (population of 16,000 to 99,999)	246
Rural or remote community (population of 15,999 or less)	184
Reside on a First Nations, Metis, or Inuit reserve/settlement	36
I prefer not to answer this question	12
Canadian province or territory	
British Columbia	203
Alberta	143
Saskatchewan	72
Manitoba	68
Ontario	410
Quebec	104
Nova Scotia	49



New Brunswick	25
Newfoundland and Labrador	41
Prince Edward Island	14
Northwest Territories	7
Yukon	4
Nunavut	2
I live outside of Canada	6
Language	
English	973
French	113
An Indigenous language	10
Other	52
Ethnic Group	
White	699
Black, Indigenous and Person of Colour TOTAL	449
Black	48
Indigenous	280
Two-spirited	152
Person of Colour	121
Gender*	
Woman	610
Man	493
Cisgender	12
Transgender	5
Non-binary	8
I prefer not to answer this question	18
I prefer to describe myself as	2
Education*	
Less than high school	33
High school or equivalent	211
Some college or university	224
College or university graduate	673
I prefer not to answer this question	7





Socioeconomic status (Annual income)*	
\$40,000 or lower	224
\$40,001 - \$80,000	429
\$80,001 or higher	442
I prefer not to answer this question	53
Social capital (How far do you have to travel to see a health care provider?)	
0-10 kilometres (0-6 miles)	453
11-25 kilometres (7-15 miles)	354
26-50 kilometres (16-31 miles)	189
51-100 kilometres (32-62 miles)	77
101-250 kilometres (63-155 miles)	45
251-500 kilometres (156-311 miles)	22
More than 500 kilometres (more than 311 miles)	8
Plus (Age)	
before 1910	2
between 1910-1929	7
between 1930-1949	94
between 1950-1969	345
between 1970-1989	386
between 1990-2009	312
2010 to present	2
Time since diagnosis	
0-1 year	173
2-5 years	445
6-10 years	278
11-15 years	105
More than 15 years	140
I did not receive a diagnosis of arthritis	7
Plus (Type of arthritis)*	
Adult-onset Still's disease	57 (5%)
Ankylosing spondylitis	80 (7%)
Fibromyalgia	145 (13%)
Gout	180 (17%)
Juvenile idiopathic arthritis	112 (10%)
Lupus	89 (8%)

Non-radiographic axial spondyloarthritis (not visible on X-ray)	57 (5%)
Osteoarthritis	398 (45%)
Polymyalgia rheumatica	88 (8%)
Psoriatic arthritis	154 (13%)
Rheumatoid arthritis	386 (34%)
Scleroderma	81 (7%)
Sjögrens syndrome	83 (7%)
Vasculitis	61 (5%)
Do not know	83 (7%)
Other	31 (3%)



## Arthritis Consumer Experts (ACE)

### Who we are

Arthritis Consumer Experts (ACE) and its team members acknowledge that they gather and work on the traditional, ancestral and unceded territory of the Coast Salish peoples - xʷməθkʷəy̓əm (Musqueam), Skwx-wú7mesh (Squamish), and Səlilwətaʔ/Selilwitulh (Tsleil-Waututh) Nations.

ACE operates as a non-profit and provides free research based education and information to Canadians with arthritis. We help (em)power people living with all forms of arthritis to take control of their disease and to take action in healthcare and research decision making. ACE activities are guided by its members and led by people with arthritis, scientific and medical experts on the ACE Advisory Board. To learn more about ACE, visit [www.jointhehealth.org](http://www.jointhehealth.org).

### Guiding Principles

Healthcare is a human right. Those in healthcare, especially those who stand to gain from the ill health of others, have a moral responsibility to examine what they do, its long-term consequences and to ensure that all may benefit. The support of this should be shared by government, citizens, and non-profit and for-profit organizations. This is not only equitable, but is the best means to balance the influence of any specific constituency and a practical necessity. Any amount remaining from our annual budget at year end remains with ACE and is used to support the following year's core programs to continue helping Canadians living with arthritis.

For its past 20 years, ACE has consistently honored a commitment to its members and subscribers, academic and healthcare professional colleagues, collaborators, government and the public that its work is free from the influence of its funders.

To inform ACE employees and our stakeholders, members, subscribers that we will operate our organization with integrity and abide by the highest standards of lawful and ethical behaviour, ACE has adopted this strict set of guiding principles:

- ACE requests grants from private and public organizations to support its core program and plans and allocates those funds free from influence;
- ACE discloses all funding sources in all its activities;
- ACE does not promote any "brand", product or program on any of its materials or its website, or during any of its educational programs or activities.
- ACE employees do not receive equity interest or personal "in-kind" support of any kind from any health-related organization;
- ACE identifies the source of all materials or documents used;
- ACE develops positions on health policy, products or services in collaboration with people living with arthritis, academic research community, health care providers and governments free from concern or constraint of its funders or other organizations; ACE employees do not engage in personal activities with its funders;
- Cheryl Koehn does not own stock or any financial interest in any of its private or public funders.

### Thanks

ACE thanks Arthritis Research Canada (ARC) for its scientific review of all ACE and JointHealth™ materials.



### Disclosures

Over the past 12 months, ACE received grants-in-aid from: Amgen Canada, Arthritis Research Canada, Biosimilars Canada, Canadian Biosimilars Forum, Canadian Rheumatology Association, Eli Lilly Canada, JAMP Pharma, Novartis Canada, Organon Canada, Pfizer Canada, Sandoz Canada, Teva Canada, UCB Canada, the University of British Columbia and the University of Toronto.

### Disclaimer

The material contained in this publication should not be relied on to suggest a course of treatment for a particular individual or as a substitute for consultation with qualified health professionals who are familiar with your individual medical needs. Please contact your physician for your own health care related questions.

**ACE** Arthritis Consumer Experts

#210 - 1529 West 6th Avenue  
Vancouver BC V6J 1R1  
t: 604.974.1366

[feedback@jointhehealth.org](mailto:feedback@jointhehealth.org)  
[www.jointhehealth.org](http://www.jointhehealth.org)

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