

Arthritis Consumer Experts National Survey on Arthritis and Health Literacy: Part 2

Arthritis Consumer Experts (ACE) is committed to taking action to address inequities in arthritis care and we recognize it takes the whole community to make positive change. 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, interactions with health care providers, ability to use information in decision making, self-care and how they increase health knowledge.

This JointHealthTM insight is Part 2 of the ACE National Survey on Arthritis and Health Literacy findings analysis. We take a deeper look at the responses from Black, Indigenous, and people of colour (BIPOC) versus white respondents.

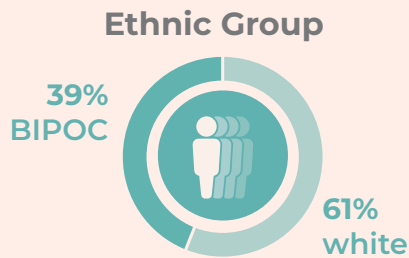


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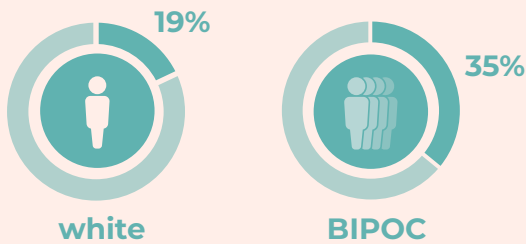
Click here to download the "Health Literacy in People Living with Arthritis: Part 2" infographic.

Who were the Survey respondents?

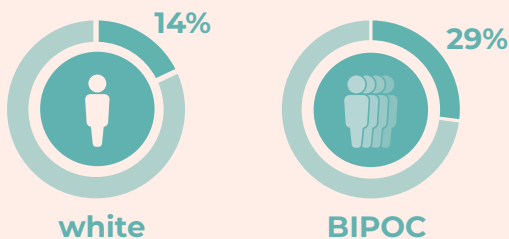


Understanding of health information

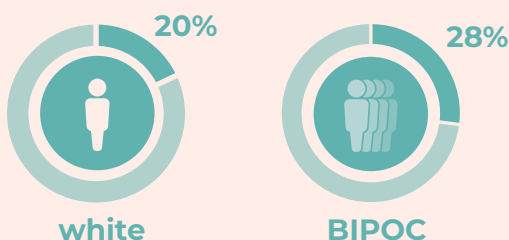
Online health information such as websites, blogs, podcasts, social media, and videos



Media such as newspaper, radio, or TV



In conversation with family, friends, colleagues



Background

What is health literacy?

The *Canadian Public Health Association Expert Panel* on Health Literacy defines health literacy as “the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life course.” The results of limited health literacy are barriers to accessing health services, development or worsening of chronic illness and preventable disease, and ineffective use of health services.¹

Health information is constantly changing and being updated and delivered in multiple ways – as online resources, information pamphlets, through videos, infographics, and podcasts. In an **Arthritis At Home interview** with Dr. Fiona Rawle, Associate Dean, Pedagogical Development and Scholarship at the University of Toronto, Dr. Rawle discusses ways to recognize fake science and health information and tips on communicating science to patients.

Who were the Survey respondents?

A total of 1,148 people responded to the Survey. These people will be referred to in this writing as “respondents.” Out of the total respondents, 449 (39%) were BIPOC and 699 (61%) were white. We received 48 responses from respondents who identified as Black, 280 from those who identified as Indigenous, and 121 from those who identified as a person of colour. For more demographic information including education, income, and type of arthritis, please refer to the **Appendix** at the end of this newsletter.

What did we find?

Understanding and using health information

Navigating the world of health information can be challenging. Information can come from online content and mainstream media sources to opinions and advice from family and friends. It’s important to understand health information and apply it to communicate effectively with health care providers and make informed decisions.

Our Survey findings show that while BIPOC and white respondents have similar levels of understanding of health information, BIPOC respondents reported higher levels of understanding when compared to white respondents. This was particularly true for information found online, in the media, and in conversations with family and friends (BIPOC vs white):

- Online health information such as websites, blogs, podcasts, social media, and videos – BIPOC at 35% vs white at 19%
- Media such as newspaper, radio, or TV – BIPOC at 29% vs white at 14%
- In conversation with family, friends, colleagues – BIPOC at 28% vs white at 20%

The ability to determine the importance and credibility of health information was also higher among BIPOC respondents (31%) when compared to white respondents (27%).

Talking with health care providers

Health information should be delivered in a way that is easy to understand to ensure people with arthritis feel included, safe, heard, and understood in conversations about their health. To understand the level of interaction between people living with arthritis and their health care providers, Survey respondents were asked how often their health care providers:

- explained health issues in a way that is easy to understand
- used medical terms or words that Survey respondent did not understand
- used visuals including pictures, drawings, models, or videos to demonstrate how to take the medication, use an assistive device or follow a technique
- listened carefully to Survey respondent
- encouraged Survey respondent to ask questions

Despite high levels of understanding, BIPOC respondents reported greater challenges with interacting with health care providers. For instance, only 12% of BIPOC respondents answered “often” when asked if health care providers explained health issues clearly, when compared to 19% of white respondents. Further, the use of medical jargon was reported to be higher during consultations among BIPOC respondents (6%) when compared to white respondents (2%). Only 16% of BIPOC respondents expressed that they felt listened to “often” when compared to 21% of white respondents.





Using information to make better health decisions

Using health information to make choices is very important. It helps people understand their health challenges, choose the best treatments, participate in physical activities that are most suitable to them, and make healthy food choices. ACE asked people to rate their ability to use information to make decisions on a scale from 1 (not confident) to 5 (very confident).

BIPOC respondents,, when compared to white respondents, reported lower levels of understanding of the purpose of each medication (32% vs 62%), how much medication to take (38% vs 70%) and experience greater challenges taking medication the way it was prescribed (20 vs 6%). Similar lower levels of understanding were observed for understanding the purpose of physical activity (28% vs 60%), knowing how, where, and when to participate in physical activity (24% vs 45%); as well as the purpose of a healthy diet (32% vs 57%) and reading food labels (20% vs 31%). There were no differences between BIPOC and white respondents in their confidence to participate in physical activity or knowledge of what foods to avoid.



Taking care of yourself

Taking care of yourself, or “self-care,” is an important part of managing arthritis. This can include seeking help from others, using reliable online resources or going to educational workshops and webinars. Doing these things help people with arthritis learn more about how to manage and take control of their health.

BIPOC respondents reported attending workshops or webinars more often than white respondents (42% vs 19%), going to support group meetings (48% vs 13%), and following self-help guides online (56% vs 48%). However, BIPOC respondents were much less willing to ask others for help than white respondents (20% vs 37%). This may suggest that they may be facing a cultural barrier when looking for help. According to a 2017 review by the Wellesley Institute, receiving care in a language you don’t understand often leads to poorer health outcomes. These include a higher risk of receiving inappropriate medical testing, an increased risk of hospitalization and adverse medication reactions, and decreased patient satisfaction².

Learning more about health and arthritis

Increasing health knowledge and skills supports people with arthritis to better learn about new medication and non-medication treatments, understand research, and deal with changes in health. ACE asked people how they want to improve their health literacy and most reported they preferred learning from a health care provider. However, there were some discrepancies between BIPOC and white respondents.

BIPOC respondents (more often than white respondents) selected:

- “1 on 1 counselling” (35% vs 30%)
- “Online community or support groups” (42% vs 19%)
- “From other patients” (19% vs 12%)

White respondents (more often than BIPOC) selected:

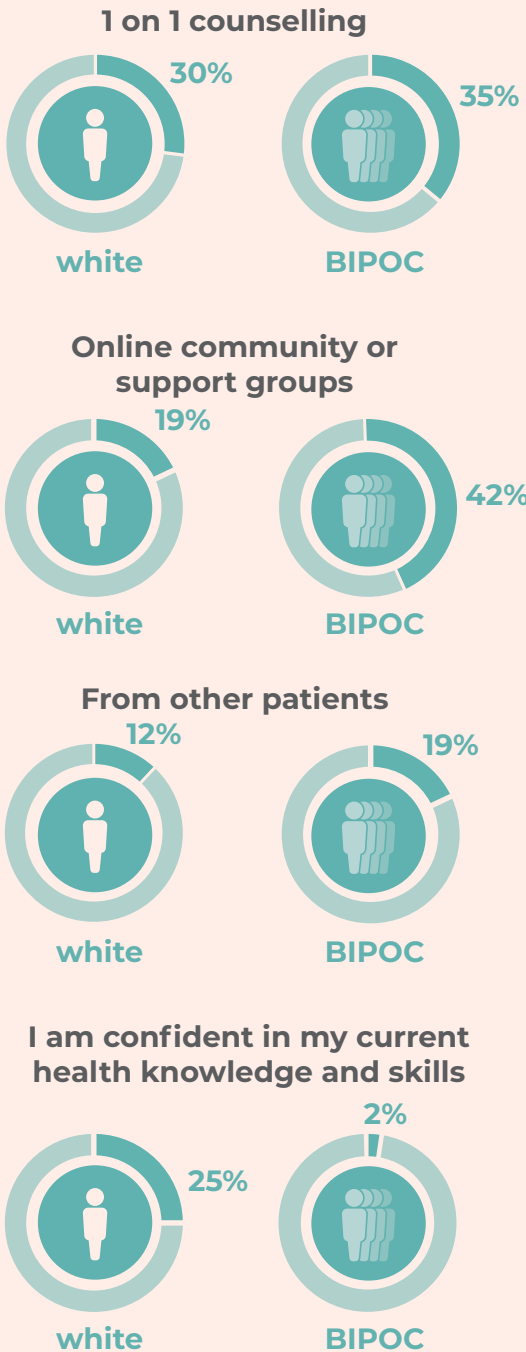
- “I am confident in my current health knowledge and skills” (25% vs 2%)


How can ACE’s Survey results inform arthritis care in Canada?

The *Arthritis Consumer Experts Health Literacy Survey Part 2* provides valuable insights into the challenges and needs of BIPOC individuals living with arthritis. It shows us how health literacy is very important to the self-care of arthritis and the various experiences using health information and learning preferences among people living with arthritis in the BIPOC community.

Our findings show that BIPOC and white respondents have similar levels of understanding of health information. However, BIPOC respondents reported facing disproportionate challenges when talking with health care providers and feeling less listened to during interactions. BIPOC respondents also reported facing barriers when navigating health care services and challenges with medications, physical activity, diet, and self-care due to the inequitable policies and structures that are in place. Interestingly, our findings revealed that BIPOC respondents (when compared to white), have unique preferences when it comes to gaining knowledge and were much less willing to ask others for help. This may suggest BIPOC respondents face barriers when looking for help and highlights the need for health

How do you want to improve your health literacy?





care providers to provide appropriate and sensitive care to those with diverse cultural and linguistic backgrounds. The creation of targeted resources and services that meet the needs of specific populations is a priority. These resources must be made available to patients, care givers, and health care providers at all points of a patient's journey.

Read our **Part 1 analysis** of the ACE National Survey on Arthritis and Health Literacy to learn what people living with arthritis, health care providers, and policymakers can do to support and improve health literacy.

Resources on health literacy and services for BIPOC populations can be found here:

- **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**
- **Arrive: Navigating the health care system in Canada**
- **Multicultural Mental Health Resource Centre**
- **OPTIKNEE clinical recommendations to guide rehabilitation to improve knee health and prevent osteoarthritis after a traumatic knee injury**
- **Provincial Health Services Authority: Translation Services**

References

- Health Literacy in Canada: A Healthy Understanding – Canadian Council on Learning, 2008
- Laher, N, A Sultana, A Aery, and N Kumar. Access to Language Interpretation Services and Its Impact on Clinical and Patient Outcomes: A Scoping Review. *Wellesley Institute*. (2018). <http://www.wellesleyinstitute.com/wp-content/uploads/2018/04/Language-Interpretation-Services-Scoping-Review.pdf>.

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 (please specify)	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%)

*Percentages do not add to 100% due to missing values and/or round off.



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.

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.

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