CAPA Canadian Arthritis Patient Alliance

experience · perspective · voice

Membership Survey Results

August 2017

About CAPA

- We are a grass-root, patient-driven, independent, national organization with members across Canada and supporters both Canadian and International.
- We believe the first expert on arthritis is the individual who has the disease.
- We assist members to become advocates not only for themselves but all people with arthritis.
- We facilitates links between Canadians with arthritis and their support systems through collaboration and partnerships.
- We welcomes all Canadians with arthritis and those who support CAPA's goals to become members.

About the Survey

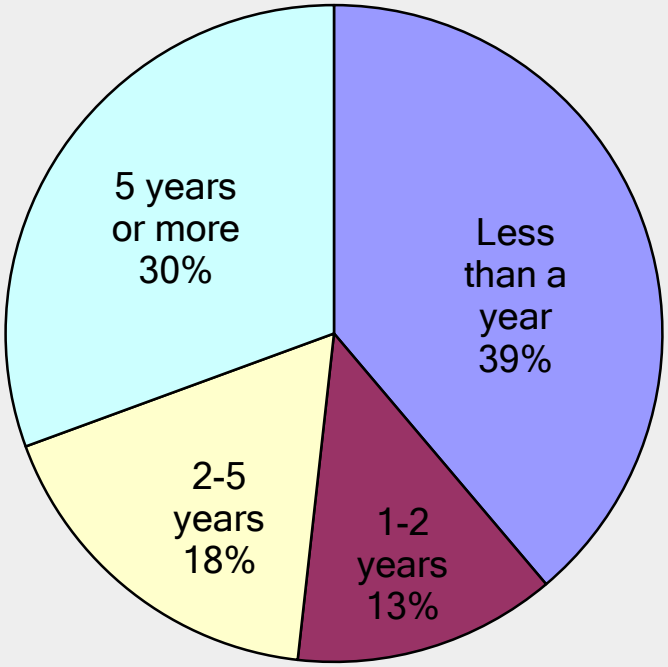
START: 1 May 2017 **END: 21 May 2017**

- Survey to understand member needs
- Draw May 31 2017 for 2 $50 VISA gift cards open to members who completed the survey
- Sent to all CAPA members on file as of April 15 2017
- Response rate: **23%** (85/369)

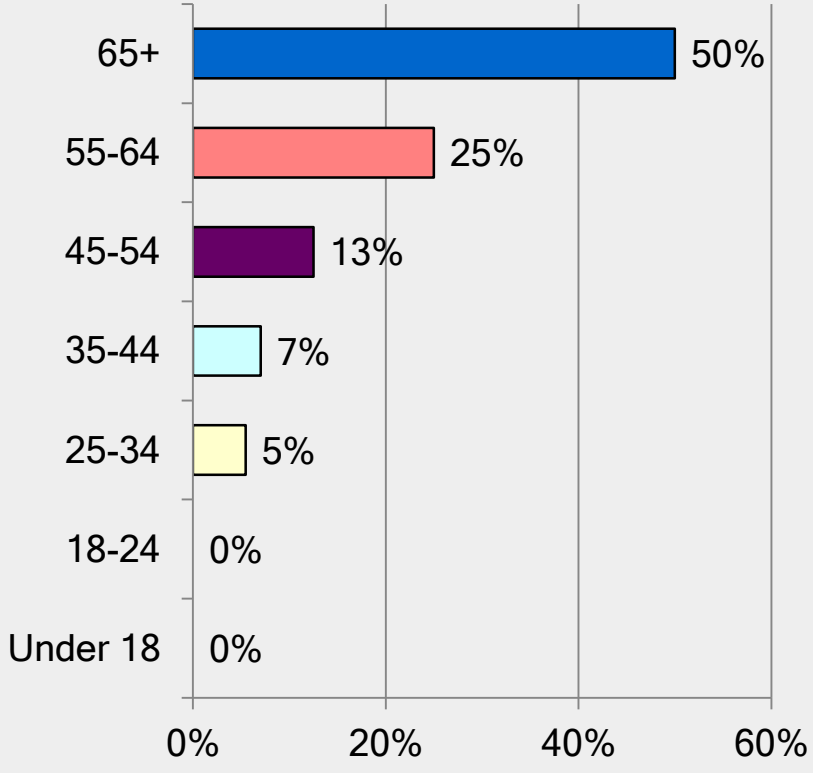
WHO ANSWERED?

75% Female, 25% Male

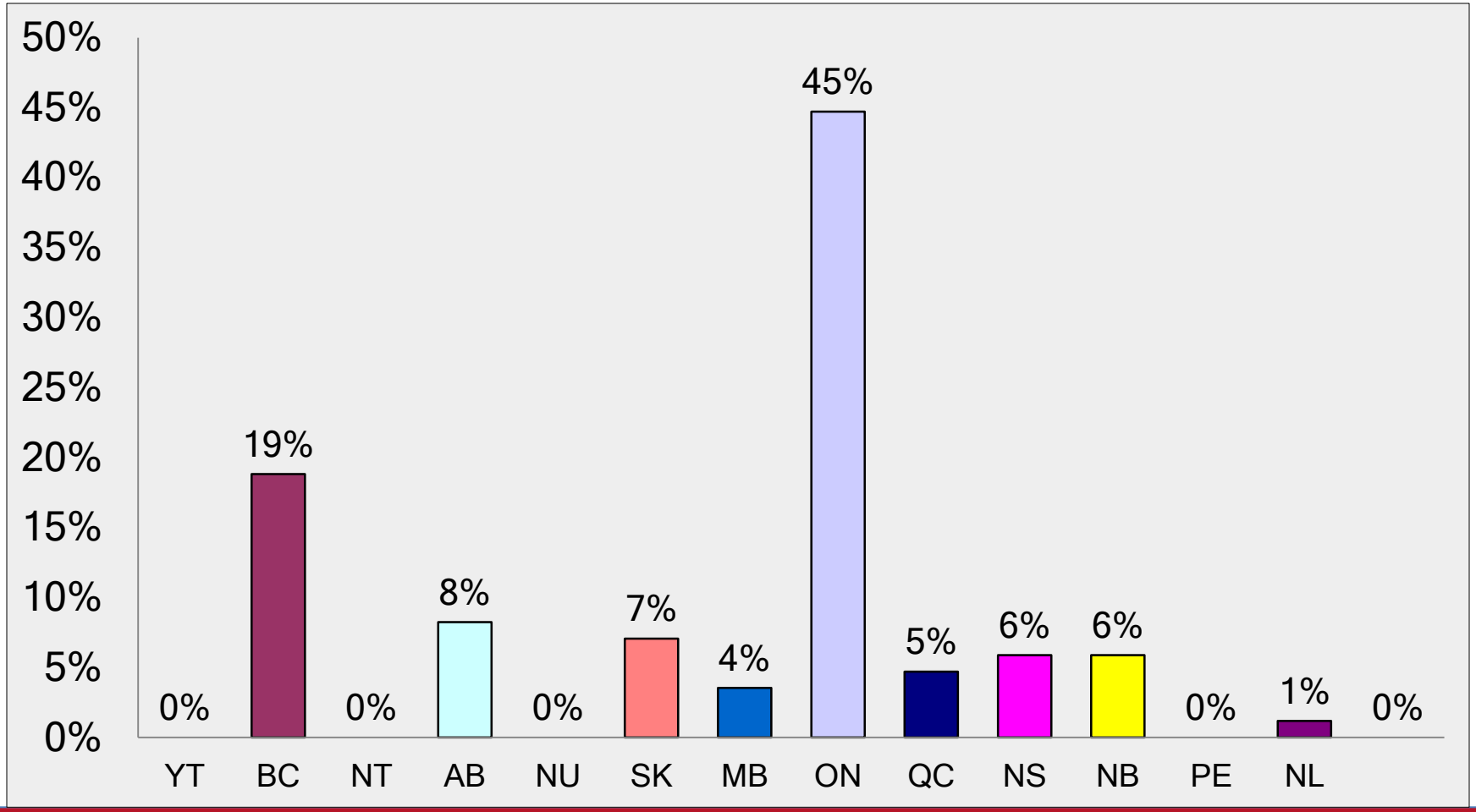
…have been members for different lengths of time



…and bring different perspectives

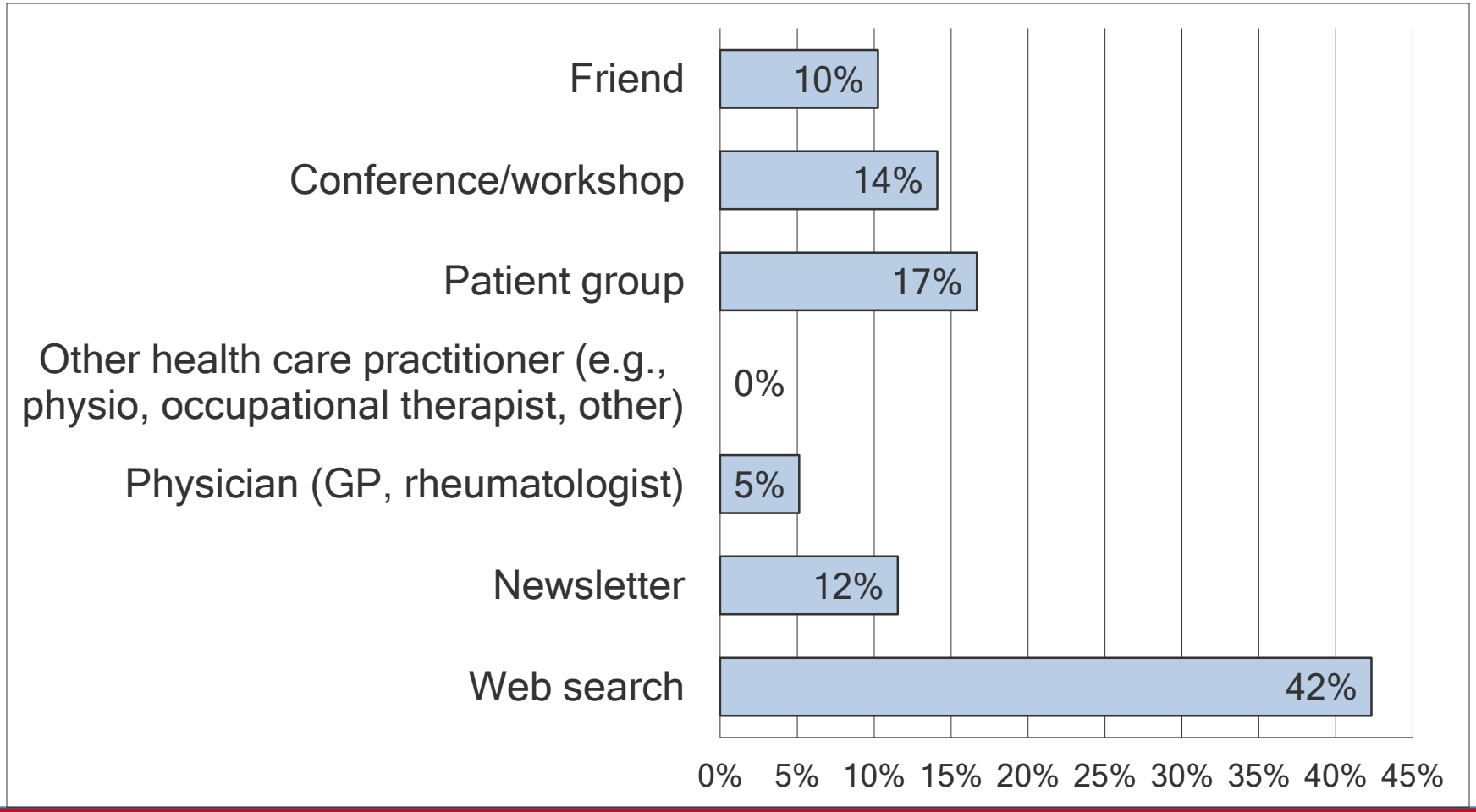


From across the country



THOUGHTS ON CAPA

Members found CAPA through…



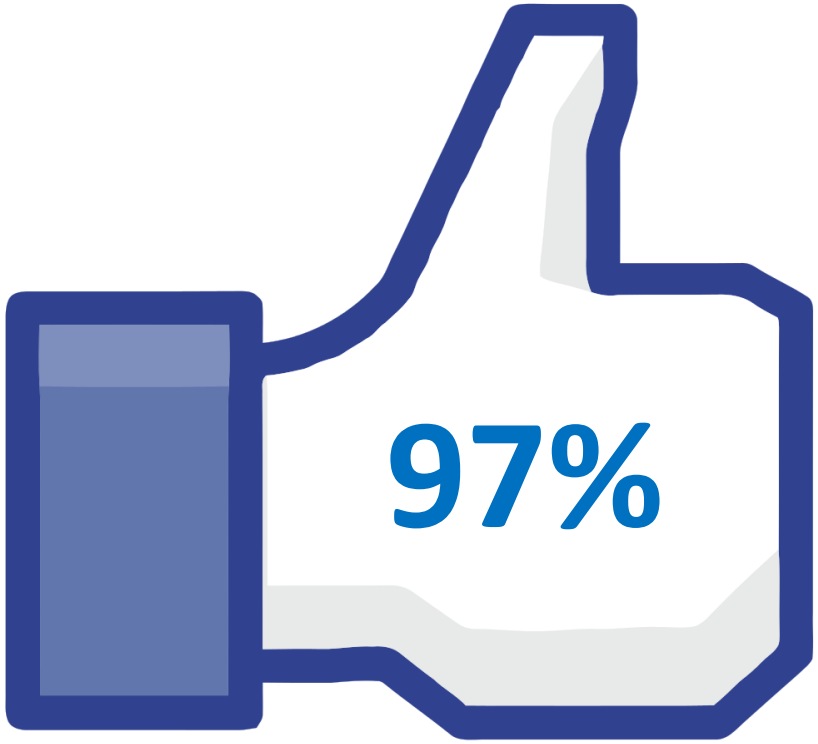
People joined CAPA to…

1. Stay informed (40%)
2. Educate themselves (32%)
3. Become an advocate (17%)

Also to:

- Connect with others
- Participate in projects

How well is CAPA meeting member expectations?

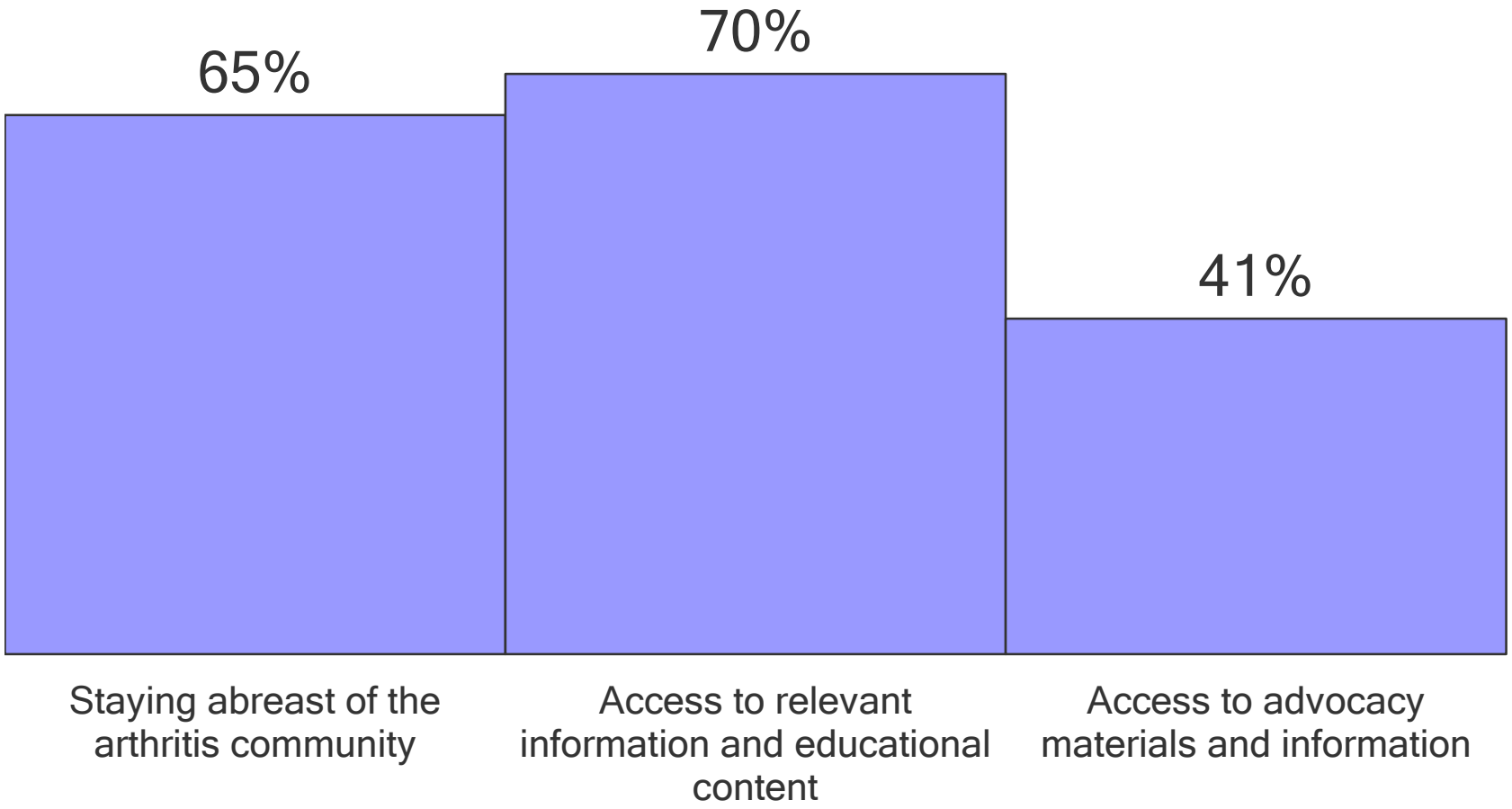


Completely or in part

Some comments…

- *CAPA is one source among many*
- *Many new to CAPA*
- *Looking for more reference material*

Benefits to CAPA membership are



CAPA initiatives

Awareness (a great deal or somewhat) of most CAPA initiatives was 40% or above, with the top two being:

CAPA Quarterly Newsletter (88%)

Arthritis Patient Charter (68%)

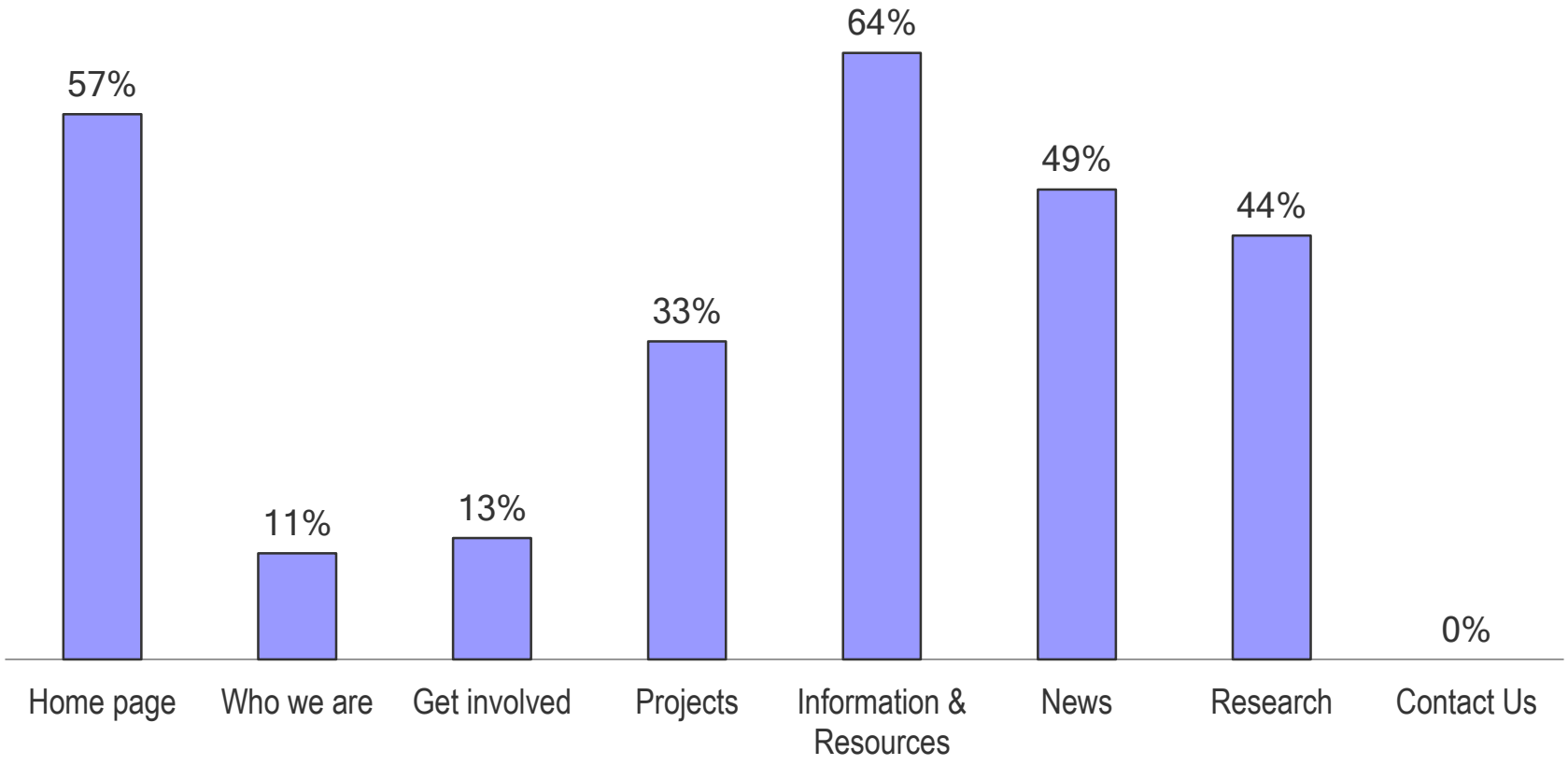
Awareness of CAPA initiatives aligned with perceptions of usefulness.

Other useful resources…

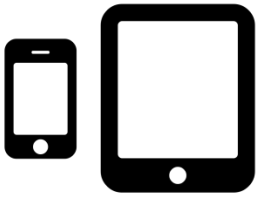
- ✓ Contacts and support
- ✓ Research
- ✓ Advocacy
- ✓ Education
- ✓ Drug input submission
- ✓ Surveys and results
- ✓ Annual plan
- ✓ Drug information
- ✓ Position papers

THE CAPA WEBSITE

Most visited the CAPA website monthly (21%) or as needed (45%). Areas of the site most visited were:



Most felt the website worked well. Some suggestions included:



Moving to mobile-friendly

Adding more pictures

Some comments…

"So many excellent online resources"
"Very good"
"Une meilleure traduction" (a better translation)

How do people find things on the Internet ?

Website search

Emails

Facebook

Twitter

Other

CAPA'S FOCUS & WHAT MEMBERS WANT

Top three…

- Arthritis drugs (77%)
- Arthritis community information (56%)
- Learning about arthritis (53%)

Is CAPA focusing on the right things?

Viewed as most important

- Patient input into drug reviews and research
- Patient and stakeholder education

All areas of focus scored over 50% support

Other suggestions for CAPA

- Patient voice in research
- Photographic book of arthritis patients
- Focus on drugs: pharmacare, trial drugs, alternatives to drugs
- Better representation from Western Canada
- Information sessions
- Focus on doctor/patient relationship

Members mostly preferred **accessing** and **receiving information** (86%), including responding to surveys (69%).

A small group was looking to be more **actively involved** with CAPA (35%).

TAKEAWAYS AND NEXT STEPS

Summary

- People are coming to CAPA to find information and be involved
- There are opportunities to build on our website to make it more accessible
- CAPA should continue to focus on its priority areas

Continue to find ways to reach new and current members

Find opportunities for members looking to be more actively engaged


THANK
YOU

Contact Us

- Find us at:

www.arthritispatient.ca

https://www.facebook.com/CAPA.Aca