



Arthritis  
Foundation

# Patient Insights

Understanding, Serving  
and Helping Millions of  
People With Arthritis

# ARTHRITIS PREVALENCE

Arthritis is preventable and treatable, not simply an unavoidable consequence of aging – yet research into arthritis is chronically underfunded.

In the United States,

**54** MILLION ADULTS

**1** IN **4** 

have doctor-diagnosed arthritis.

**2/3**

are under the age of 65, including

**300,000** CHILDREN.



It's common among athletes and those with physically-demanding jobs. OUR SERVICEMEN AND WOMEN ARE AT THE FOREFRONT OF THIS GROWING CRISIS.



**Arthritis damages vital organs and makes other conditions worse, resulting in**

**100** MILLION DOCTOR VISITS

**7** MILLION HOSPITALIZATIONS



**every year. And it contributes to early death in combination with other diseases.**

Besides preventing people from performing everyday tasks, arthritis keeps them from doing the things they love. It can cause depression and feelings of being left out of life.

**It costs the U.S. health care system**

**\$303.5** BILLION

per year. Conquering arthritis is the first step in alleviating this financial burden on our health care system.

**By reaching and listening to millions of people with arthritis, the Arthritis Foundation is capturing what matters most to patients – working together to develop resources, influence research and change systems to improve lives.**

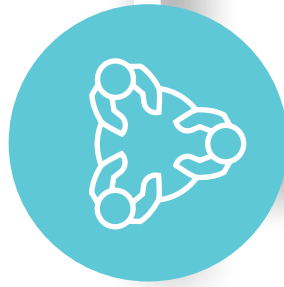


The Arthritis Foundation is the Champion of Yes. Leading the fight for the arthritis community, the Arthritis Foundation helps conquer everyday battles through life-changing information and resources, access to optimal care, advancements in science and community connections. Our goal is to chart a winning course, guiding families in developing personalized plans for living a full life – and making each day another stride towards a cure.

# POSITIVE IMPACT



We guide the arthritis community to take action through **ADVOCACY AT THE STATE AND FEDERAL LEVELS** – surpassing 100 state legislative victories since 2014 and growing the Congressional Arthritis Caucus to 146 members in 2018.



The Live Yes! Arthritis Network, created by the Arthritis Foundation, makes **CONNECTIONS BOTH IN PERSON AND ONLINE** to empower people to live their best life. People with arthritis find strength in each other, manage stress and take control of their health care.



## INFORMATION & CONNECTIONS HAVE A POSITIVE IMPACT.

People who engage with the Arthritis Foundation are taking more positive actions compared to those with arthritis who are not engaged.



52%

more likely to **SEEK TREATMENT** from a doctor

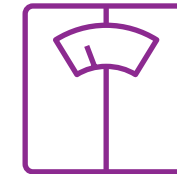
39%

more likely to **EAT HEALTHIER**



23%

more likely to agree that there are things a person with arthritis can do to **MAKE LIFE BETTER**



47%

more likely to start a **WEIGHT LOSS** program

14%

more confident in their ability to **PURSU** GOALS



SINCE 1948

\$500 +

MILLION INVESTED IN ARTHRITIS RESEARCH.

Arthritis Foundation-funded scientists were key to the discovery of biologics and other major interventions, changing the future for all forms of arthritis.



THE ARTHRITIS FOUNDATION IS  
PRESENT WHERE PEOPLE NEED US



Our national footprint aligns with  
communities of greatest need

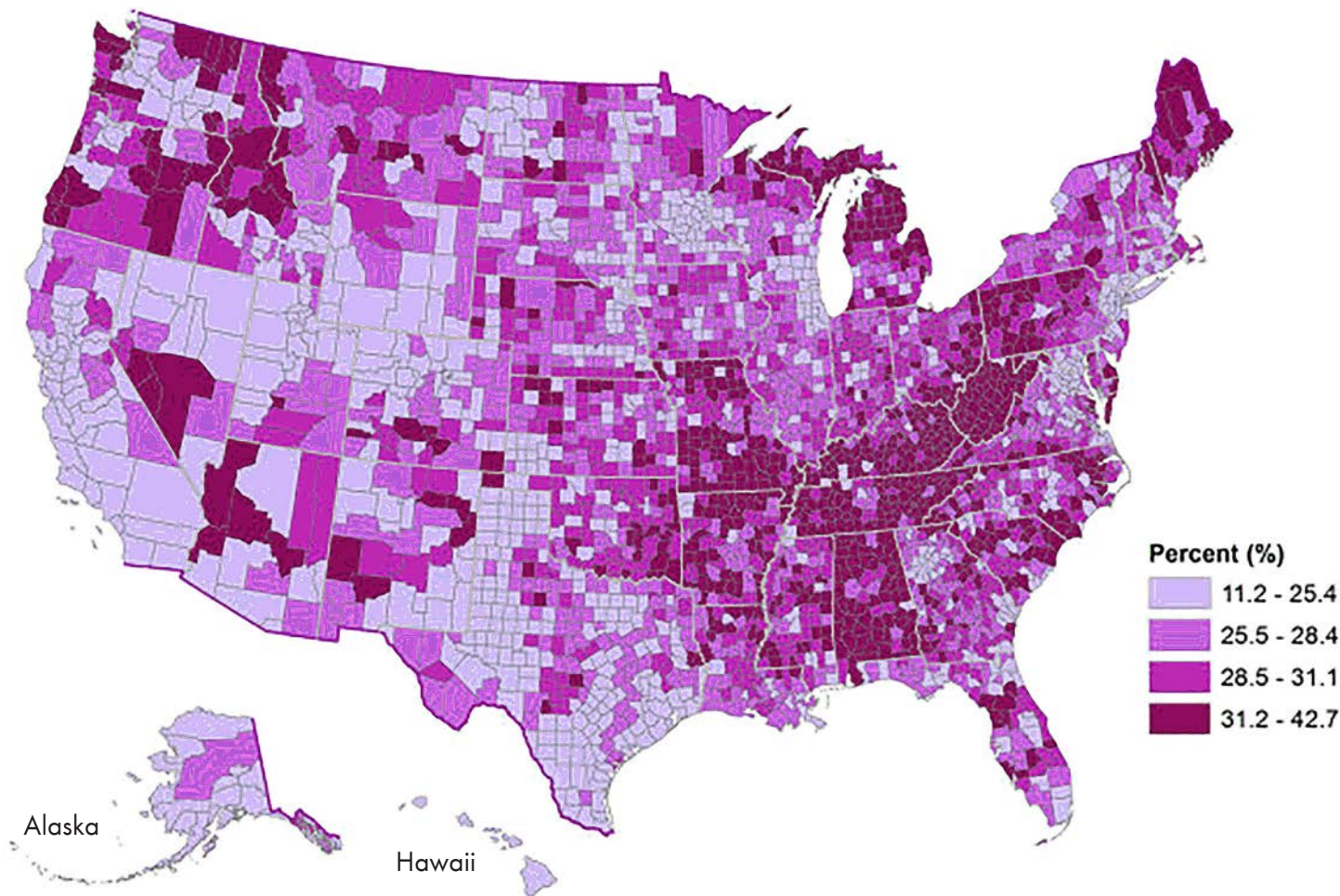
1.3  
MILLION PEOPLE



engage with digital resources  
and local events.

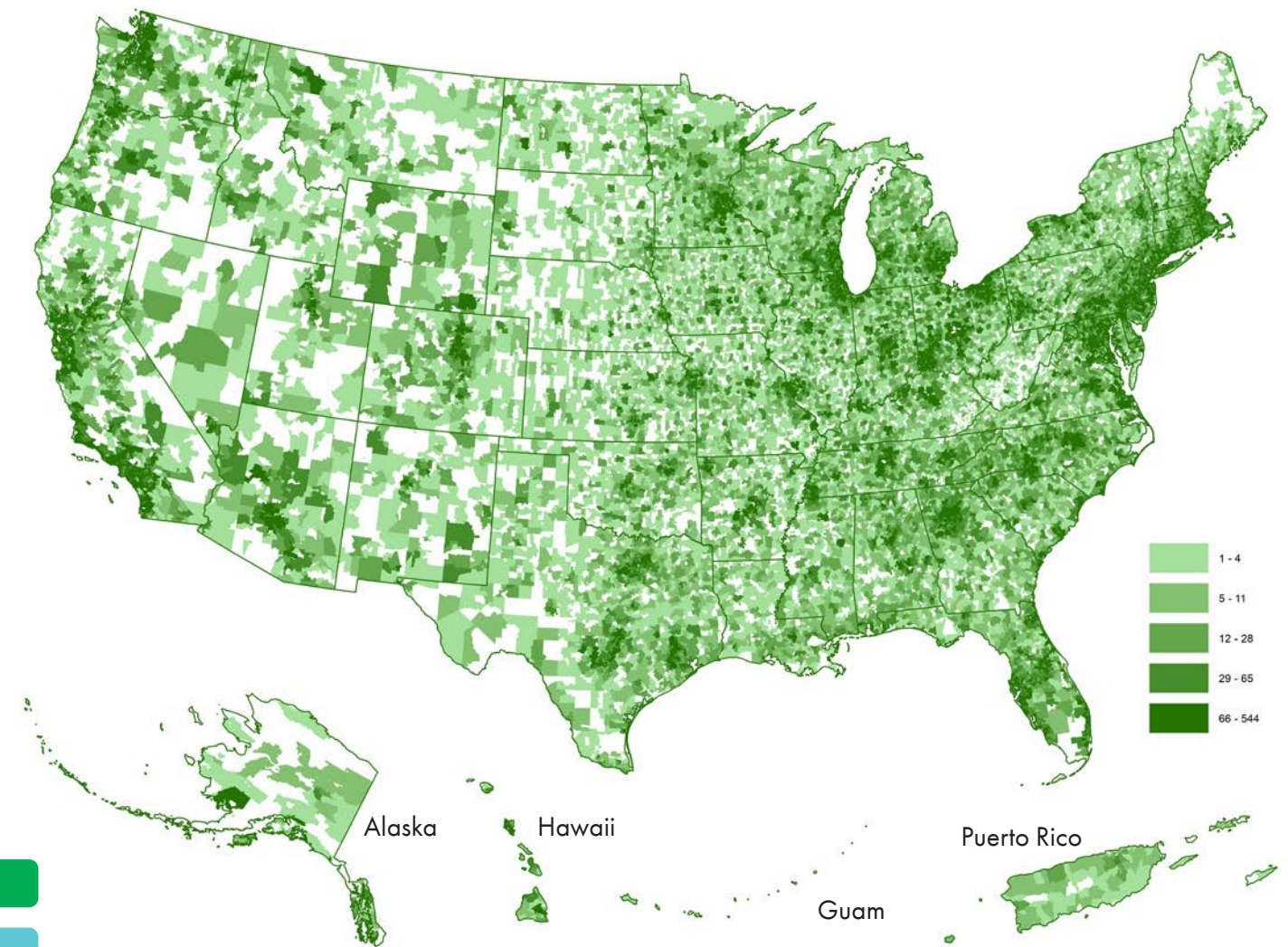
## Arthritis Prevalence Map

Source: CDC prevalence by county  
[www.cdc.gov/arthritis/data\\_statistics/state-data-current.htm](http://www.cdc.gov/arthritis/data_statistics/state-data-current.htm)

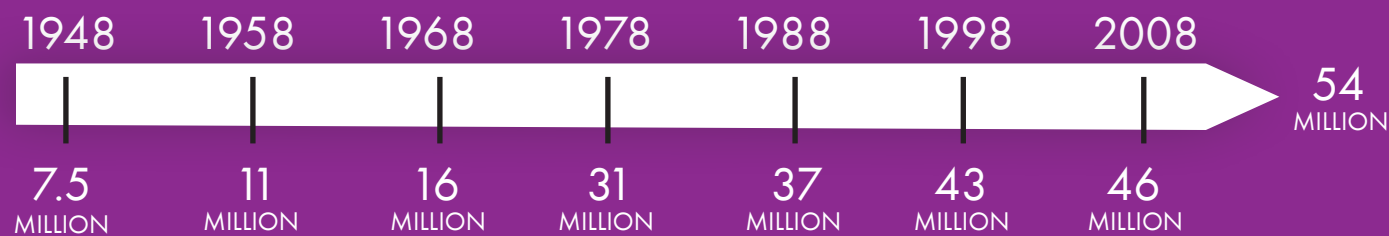


## Arthritis Foundation Reach Map

Source: Affinity Database, November 2018



Since the 1940s, the number of Americans with arthritis has risen significantly.



22 MILLION PEOPLE  
per year seek information on [arthritis.org](http://arthritis.org)



# TOP 6 AREAS THAT MATTER MOST TO PATIENTS

The Arthritis Foundation conducts over 50 surveys per year (generating between 500 – 3,000 responses per survey) to ensure our research and resources remain relevant to patient needs.



## 1 | PHYSICAL PAIN IS A BIG DEAL

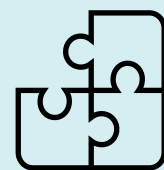
**50%** reported that PAIN IMPACTS THEM AT LEAST **10 DAYS** PER MONTH\*

**32%** reported that PAIN IMPACTS THEM AT LEAST **20 DAYS** PER MONTH\*

## 3 | NUTRITION MATTERS

**84%** believe a HEALTHY DIET IS IMPORTANT FOR MANAGING ARTHRITIS\*

## 2 | ARTHRITIS PAIN IS MORE THAN JUST PHYSICAL



**48%** FEEL DOWN, DEPRESSED OR HOPELESS\*

**57%** FEEL LITTLE INTEREST OR PLEASURE IN DOING THINGS\*

**70%** of juvenile arthritis parents FEEL NOBODY UNDERSTANDS HOW ARTHRITIS AFFECTS THEIR CHILD\*

## 4 | MEDICAL OUTCOMES ARE IMPORTANT\*

### Top 5 outcomes of interest to patients:

1. Reduce pain
2. Increase overall health
3. Slow disease progression
4. Do more of what I want to do
5. Prevent joint damage

## 5 | DAILY LIVING CAN BE DIFFICULT\*

### What people find difficult

- Get in and out of a vehicle: **68%**
- Pick something up off floor: **54%**
- Climb in and out of bed: **47%**
- Dress oneself: **42%**

### What makes products hard to use:

- Difficult to use with my hands: **68%**
- Difficult to open containers: **66%**
- Difficult to lift: **63%**
- Too heavy to use/push: **61%**

## 6 | ACCESS IS KEY\*

### Top 6 insurance issues/challenges:

1. Prior authorization
2. High deductibles
3. High coinsurance for medications
4. High premiums
5. Changes to drug formulary
6. Step therapy (fail first)

### Top 6 reasons why patients have difficulty taking their medications:

1. Side effects/how the meds make them feel
2. Cost
3. Problems with pharmacy or mail order delivery
4. Unexpected prescription charge
5. Difficulty with self-injection
6. Limited or no access to doctor or health care professionals



\*Based on Arthritis Foundation original research, backed by Nielsen/Harris Poll, patients have shared what matters most to them.

# Live Yes!<sup>SM</sup> Arthritis Network

## Network PROMISE

The Live Yes! Arthritis Network, created by the Arthritis Foundation, makes connections both in person and online to empower people to live their best life. People with arthritis find strength in each other, manage stress and take control of their health care.

## Network AGENDA

The Arthritis Foundation's Live Yes! Arthritis Network is transforming how people with arthritis live life with less pain and are more active in their care.

## Network IMPACT

The Arthritis Foundation's Live Yes! Network impacts 3 key areas of Patient-Reported Outcomes (PROs). People with arthritis will experience:

- **Improved Physical Health** – Participants will function better and be able to carry out more daily activities with less pain interference.
- **Improved Emotional & Social Health** – Participants will better manage stress and depression to improve their enjoyment of life. They will connect with others who share their same journey to boost a sense of belonging.
- **Better Experience of Care** – Participants will gain tools to proactively take control of their care by better communication with their health care team.

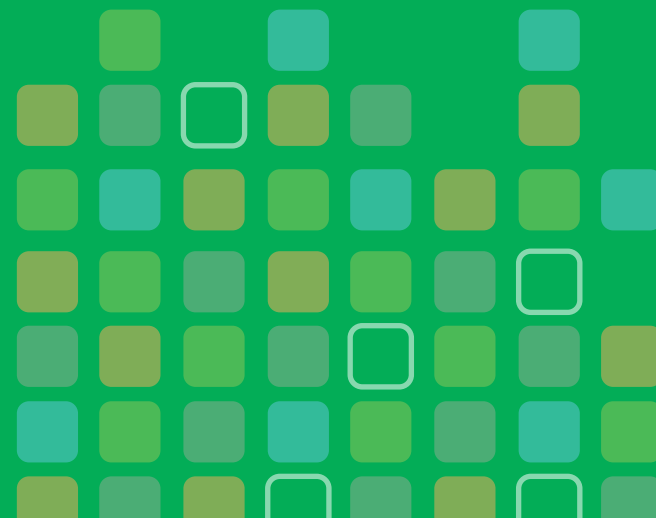


# PERSONAL APPROACH

## Patient-Reported Outcomes

The Live Yes! Arthritis Network provides real-time Patient Reported Outcomes that will shape the future of arthritis care and treatment. These PROs serve three distinct needs:

1. Allow patients to better understand and track their health over time.
2. Enable the Arthritis Foundation to tailor programming to specific market needs based on participants' aggregate data.
3. Help researchers understand patient health trends – leading to more effective treatments.



# LIVE YES! INSIGHTS

In 2018, the Arthritis Foundation launched an initial set of Patient-Reported Outcome Measures comprised of established, research-backed measures. RESULTS WERE POWERFUL.

Within 2 weeks,

# 5,040

PEOPLE PARTICIPATED  
IN THE SURVEY.

## The survey measured three primary domains:



Physical Health



Emotional Health



Experience of Care

In addition to getting a national/average baseline of results across these domains, the Foundation was able to look at results market by market. Based on findings, local markets will be able to offer targeted programming to move the needle in their area.

Some key findings include:

## TOP 4 ABOVE THE NATIONAL AVERAGE IN OUR PRIMARY DOMAINS

### Physical Health

Massachusetts  
Pittsburgh  
Colorado  
DC Metro

### Emotional Health

DC Metro  
Greater Chicago  
Pittsburgh  
Colorado

### Experience of Care

Alabama & Mississippi  
Northern New England  
Los Angeles  
Kansas

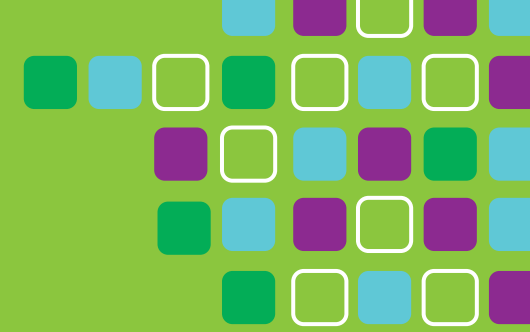
## DISEASE TYPES

Osteoarthritis | 30%  
Rheumatoid Arthritis | 22%  
Fibromyalgia | 9%  
Osteoporosis | 7%  
Psoriatic Arthritis | 4%  
Sjogren's Syndrome | 4%  
Ankylosing Spondylitis | 3%  
Juvenile Arthritis  
persistent to adulthood | 2%  
Gout | 2%  
Lupus | 2%  
Unknown | 2%  
Other | 13%

## AGE

75+ | 13%  
65-74 | 29%  
55-64 | 28%  
45-54 | 16%  
35-44 | 7%  
34 or younger | 7%

# TAKING PATIENT-REPORTED OUTCOMES TO THE NEXT LEVEL



**The Arthritis Foundation is not only leveraging patient insights, stories and self-reported outcomes to influence internal strategies, but to influence external stakeholders and systems as well. A few highlights:**



## **OA Patient-Focused Drug (PFDD) Meeting**

The Arthritis Foundation hosted an OA Patient-Focused Drug Development (PFDD) meeting in the Washington, D.C., area on March 8, 2017. This meeting provided the U.S. Food and Drug Administration (FDA), drug developers, health care providers, academic researchers and other stakeholders an opportunity to hear directly from patients, patient advocates and caretakers about the signs and symptoms that matter most to them. OA patients shared just how much this disease impacts their lives, as well as the gaps in treatment and what they are looking for in ideal, new treatment options.

**Results: FDA released new OA guidance for industry citing the shortcomings of current study endpoints to address how patients “function and feel.”**



## **JIA Patient-Focused Drug (PFDD) Meeting**

Hundreds of patients and their families, FDA staff, industry leaders and researchers convened in Washington, D.C., to participate in the externally-led JIA Patient-Focused Drug Development (PFDD) meeting on August 2, 2018. This meeting provided an opportunity for patients, patient advocates and caretakers to talk about the symptoms and issues that matter most to them. JIA parents and their families shared information about the impact of JIA on daily life, the symptoms that are most challenging, experiences with currently available treatments and the need for new and different treatments.

**Results: A written report will be published in early 2019, setting the stage for deeper community engagement between regulators, patients, researchers and the Arthritis Foundation.**



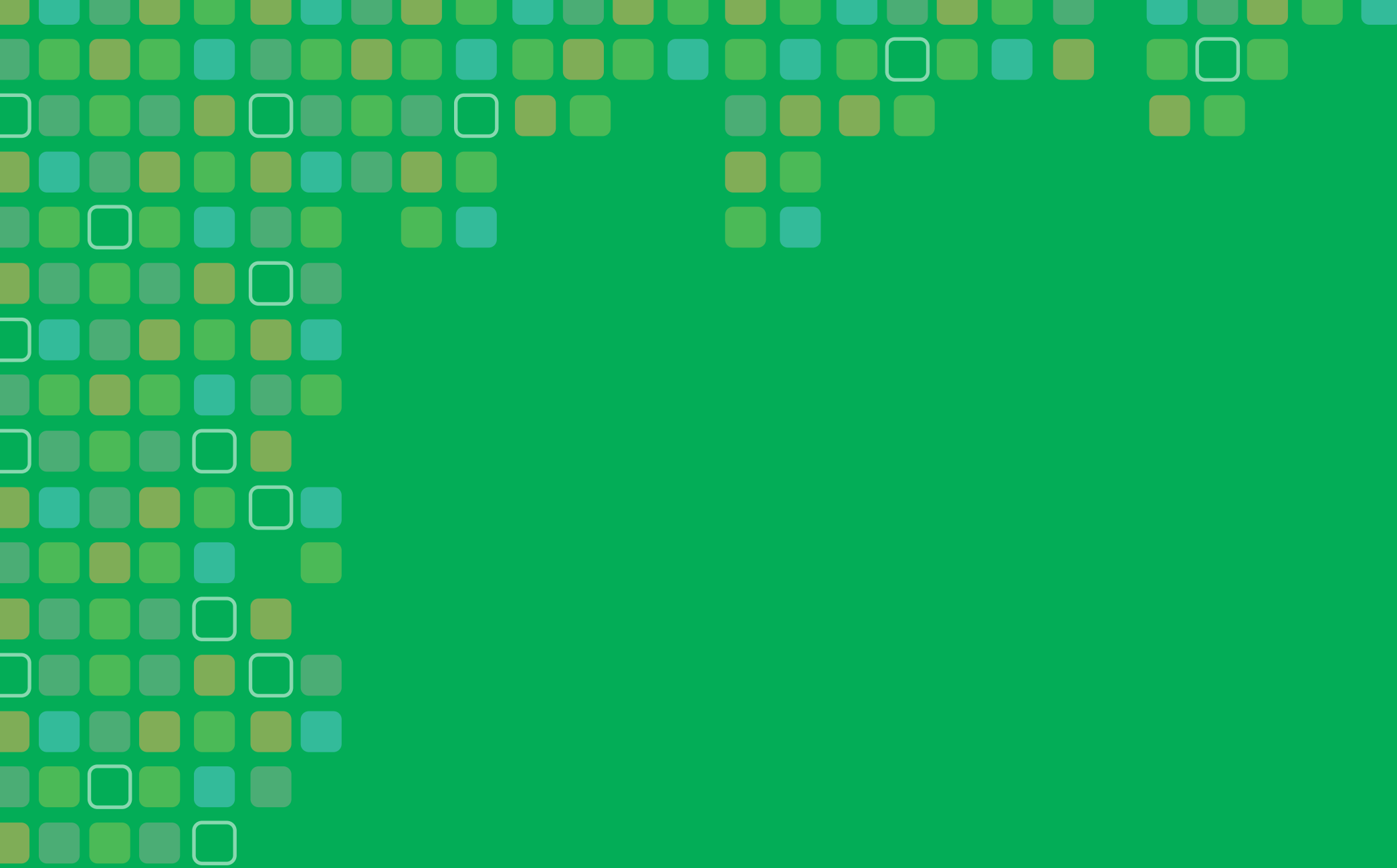
## **Influencing the Institute for Clinical and Economic Review (ICER)**

On March 24, 2017, after many months of review, the Institute for Clinical and Economic Review (ICER) held a public meeting in Boston, MA, to discuss evidence findings on treatments for rheumatoid arthritis (RA). ICER is a nonprofit organization that reviews the effectiveness of medications and their costs.

During the meeting, the Foundation played a vital role, presenting patient-centered research, asserting the patient voice and displaying strong leadership on behalf of the arthritis community. We presented data from our two patient surveys conducted over the previous months (3,745 respondents total), helping the panel better understand innovative biologic therapies, patient treatment perspectives and utilization management statistics. Panelists were shocked to learn that almost half of the surveys’ respondents had to go through step therapy and, of those, 22 percent had to repeat the steps when their insurance changed, even if they were stable on their drug.

Members of our advocacy program – Anna Legassie, Renay Houlem and Jen Melanson – also played a critical role at the ICER meeting, powerfully representing the patient perspective. Every voting member of the ICER panel noted that our Advocates’ testimony significantly impacted their knowledge and understanding of the issues.

**Results: ICER deemed it did not have enough evidence to determine that a given biologic was more cost-effective than another.**



#### References

1. Arthritis Foundation Consumer Needs Study, conducted by Nielsen/Harris, July 2016 (AF members n=722 & Non-AF members n=615)
2. Arthritis Foundation Consumer Usage Study, conducted by Nielsen/Harris, March 2016 (Diagnosed with Arthritis: n=706; General Public: n=714)
3. Arthritis Foundation Advocacy Priorities Report, September 2018 (n= 1,744)
4. Arthritis Foundation Nutrition Survey, May 2018 (n= 855)
5. Arthritis Foundation OA Patient-Focused Drug Development Survey & Focus Group Report, March 2017 (n=345)
6. Arthritis Foundation Patient Reported Outcome Survey, October 2018 (n= 5,040)
7. Arthritis Foundation survey of rheumatoid arthritis patient treatment experiences, for Discussion with ICER, November 2016 (n= 3,186)
8. Arthritis Foundation survey to determine impact of innovative therapies on rheumatoid arthritis patients, for Discussion with ICER, December 2016 (Biologic naïve for 5 years or more n=222 & Biologic experienced within 5 years n=337)
9. Center for Disease Control (CDC): [https://www.cdc.gov/arthritis/data\\_statistics/arthritis-related-stats.htm](https://www.cdc.gov/arthritis/data_statistics/arthritis-related-stats.htm)

To learn more about the  
Live Yes! Arthritis Network, go to:

**[arthritis.org/LiveYes](https://arthritis.org/LiveYes)**



