

A Mandate for Action

Live Yes!

INSIGHTS
LIVE

A Live Yes! INSIGHTS Event

New York City • March 3, 2020

Raj Karia
Network Leader,
New York City
Leadership Board
of Directors

Welcome

Evening Agenda

5:15 pm - Welcome and Program

Raj Karia, Network Leader Arthritis Foundation's Board of Directors

Ann Palmer, Arthritis Foundation CEO

Cindy McDaniel, Arthritis Foundation Senior VP Consumer Health & Impact

Shannan O'Hara Levi, Patient Leadership Council Member

Dustin Levi, Shannan's husband

Chris Altizer, Facilitator

6:00 pm - A Mandate for Action Discussion

7:00 pm - Dinner Served

7:45 pm - Interactive Showcase and Dessert Reception

8:30 pm - Event Concludes

Ann M. Palmer
President & CEO

A Mandate for Action

Mission Statement


The Arthritis Foundation is boldly pursuing a cure for **America's #1 cause of disability, while championing the** fight against arthritis with life-changing information, advocacy, science and community connections.

Establish the Arthritis Foundation as

Champion of Yes!



Helping people overcome “No” and say “Yes” to the things they love to do



YOU ARE
NOT
ALONE

Helping people create personalized plans for YES

Our Focus: The 4 Pillars



Scientific Discovery

Accelerate progress in new and better diagnostics and treatments, achieve results faster with an inclusive approach.



Help & Support

Make a major difference in the lives of people with arthritis through personalized attention and expert guidance – whenever, wherever.



Advocacy & Access

Be the most respected, authoritative voice for people with arthritis to regulators, insurers, employers and policy makers.



Juvenile Arthritis

Meet the unique needs of JA families with practical services and support to improve their lives every step of the way.

Advocacy & Access

We've helped secure more than 135
state legislative victories in all 50
states since 2014

Our Network includes 150,000
Advocates and 1,400 Ambassadors

Juvenile Arthritis

More than 34,000 children and caregivers have benefited from our annual National JA Conference since 1984

In the past five years, we've
invested \$25 million to boost JA
research with CARRA



Scientific Discovery

Over the past seven decades,
we've invested \$500+ million
into arthritis research, leading
to life-changing discoveries

Focused On:

- Advancing OA Treatment
- Childhood Arthritis
- Cultivating a new generation of rheumatologists
- Improving quality of care

Of those who have interacted with the Arthritis Foundation

3 in 4

**say our organization
has had a positive
impact on their lives**



and nearly all say the information is helpful.

Goals of the Network

- Personalized experience from Day 1
- Unleash the power of our community
- Improve care
- Influence research agenda



Network Impact: Building on Three Focus Areas

Improved
Physical Health

Improved Emotional
& Social Health

Better Experience
of Care

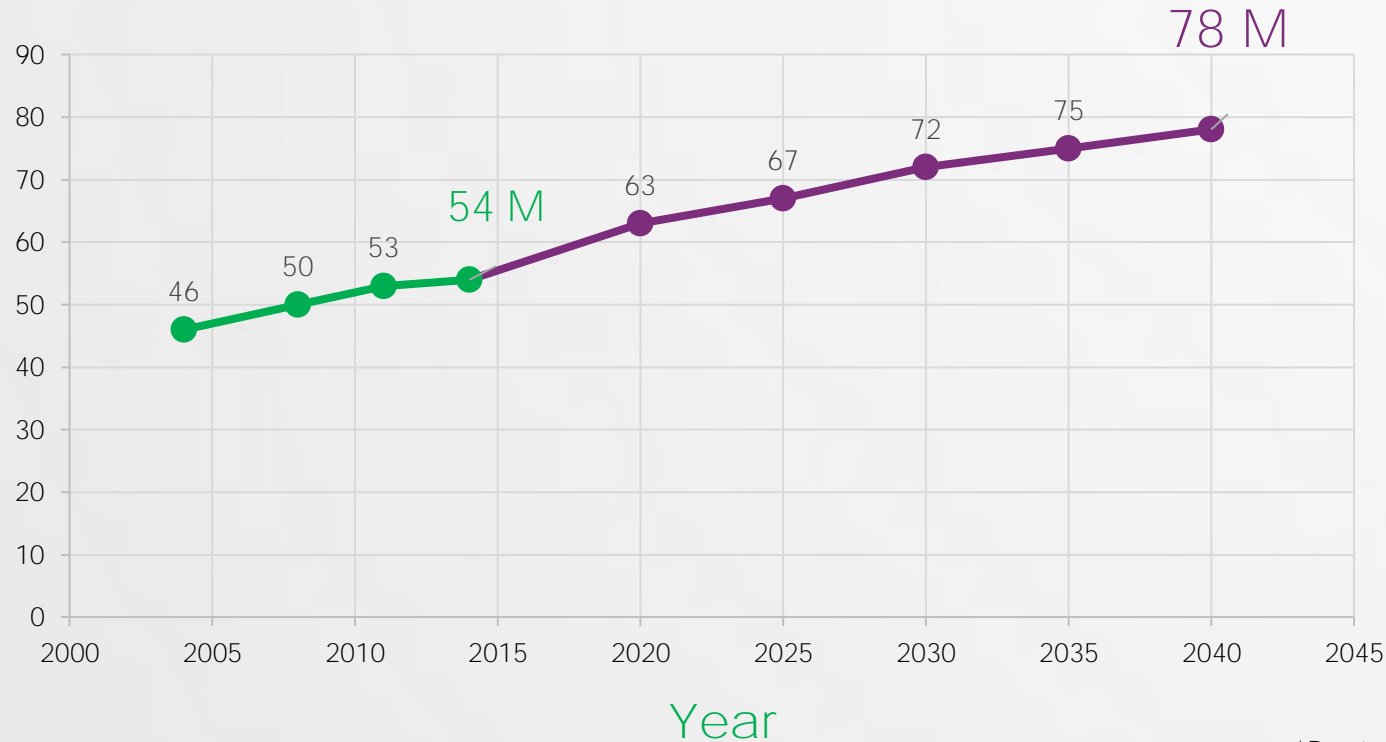
Arthritis.org + Helpline: Front Door to the Network

Your Self, Your Health, Your Life
We offer people with arthritis the right tools and resources they need to help understand their disease, take action to improve their quality of life and be a part of finding a cure.



People Diagnosed With Arthritis and Future Projections*

People (millions)



● Diagnosed
● Projected

*Doctor diagnosed

Source: National Health Interview Survey, 2023-2025; www.cdc.gov/vitalsigns/arthritis

What we know

about people with arthritis...

29% report fair/poor health status
(33% = good; 39% = very good or excellent)

38% are obese
(33% = overweight; 25% = underweight/normal weight)

25% have heart disease

19% have diabetes

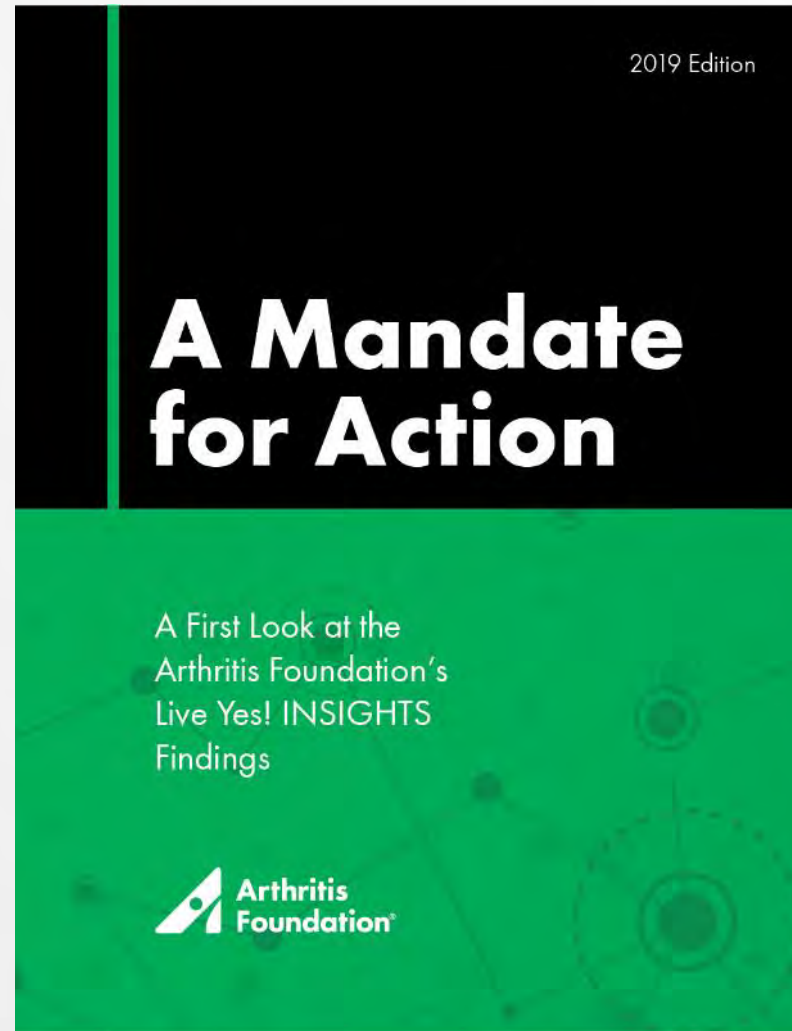
Listening to Patients

Live Yes!
INSIGHTS **LIVE**

Live Yes! INSIGHTSSM

Received 24,000 Live Yes!
INSIGHTS assessments

First 18,000 included in A
Mandate for Action report



Integrity in Research

Establishing an organizational structure to support our work:

- Internal review board
- Voluntary participation and informed consent
- Data security and monitoring

Live Yes! INSIGHTS: How We Got Here

Domain Selection Process:

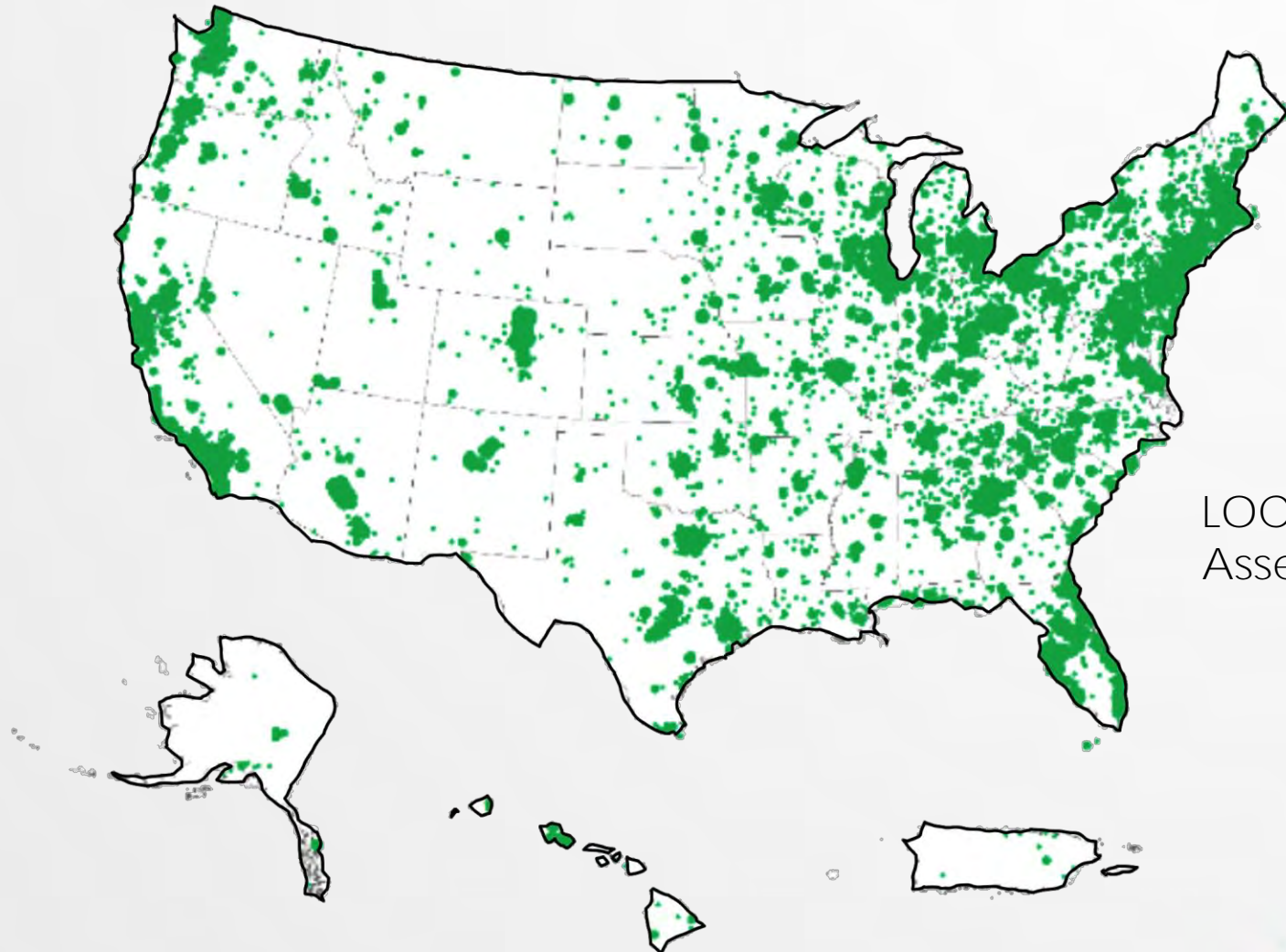
- Three broad domains were selected based on previous research and interviews
- Domains: physical health, emotional and social health, and experience of care
- Developed new PRO measuring profiling tool (named PROMPT) to narrow measures from 40 down to nine (three per domain)
- Twenty-two patients worked as a committee to review and vote on the measures that best reflected the life of a person living with arthritis

Measures Selected:

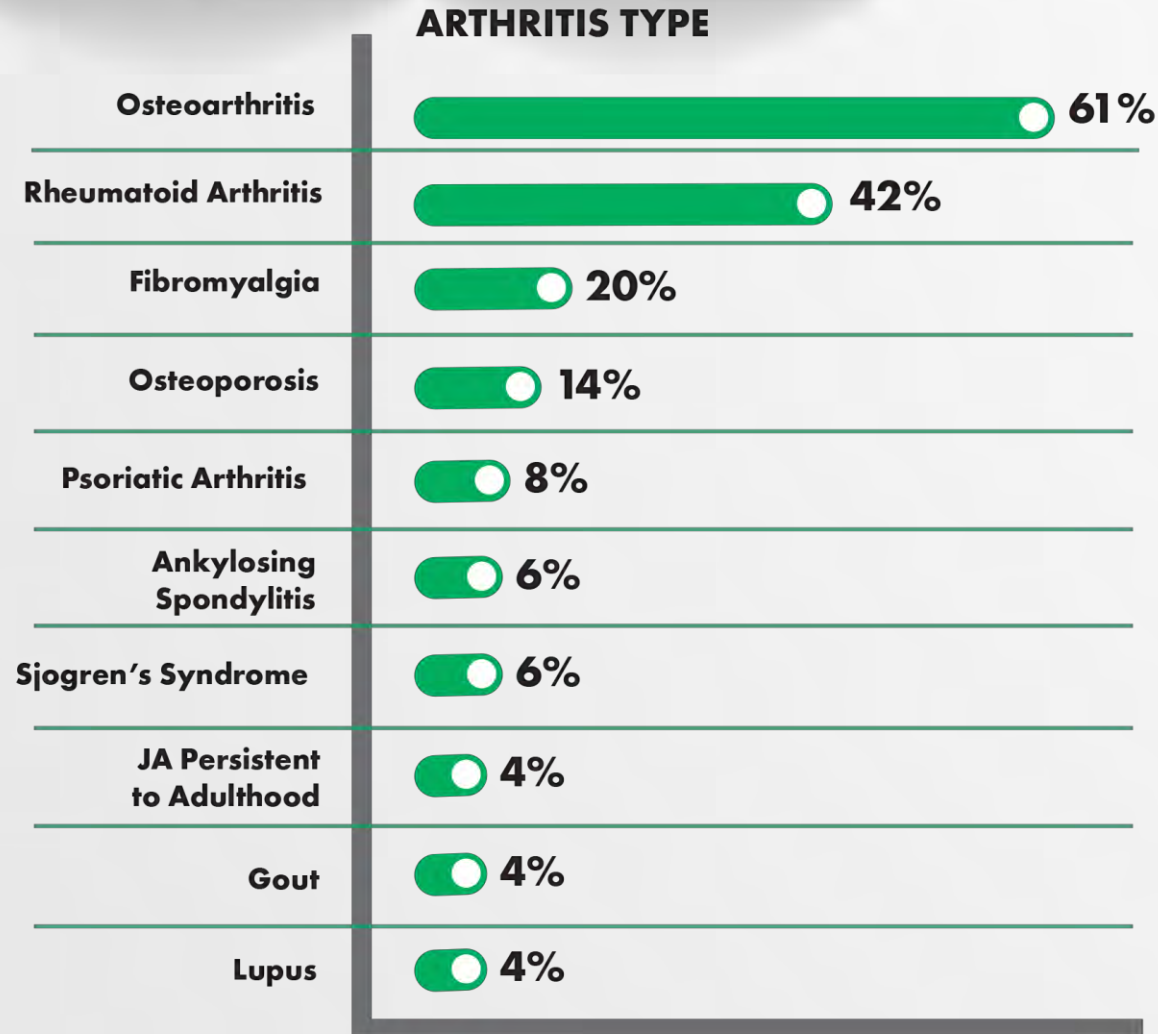
- PROMIS-29 profile v 2.0
- PROMIS Emotional Support Short Form v 2.0
- Health Care Empowerment Questionnaire

Live Yes! INSIGHTSSM

Assessments
empowering
people, no
matter where
they live, to lend
their voice



LOCATION OF
Assessments



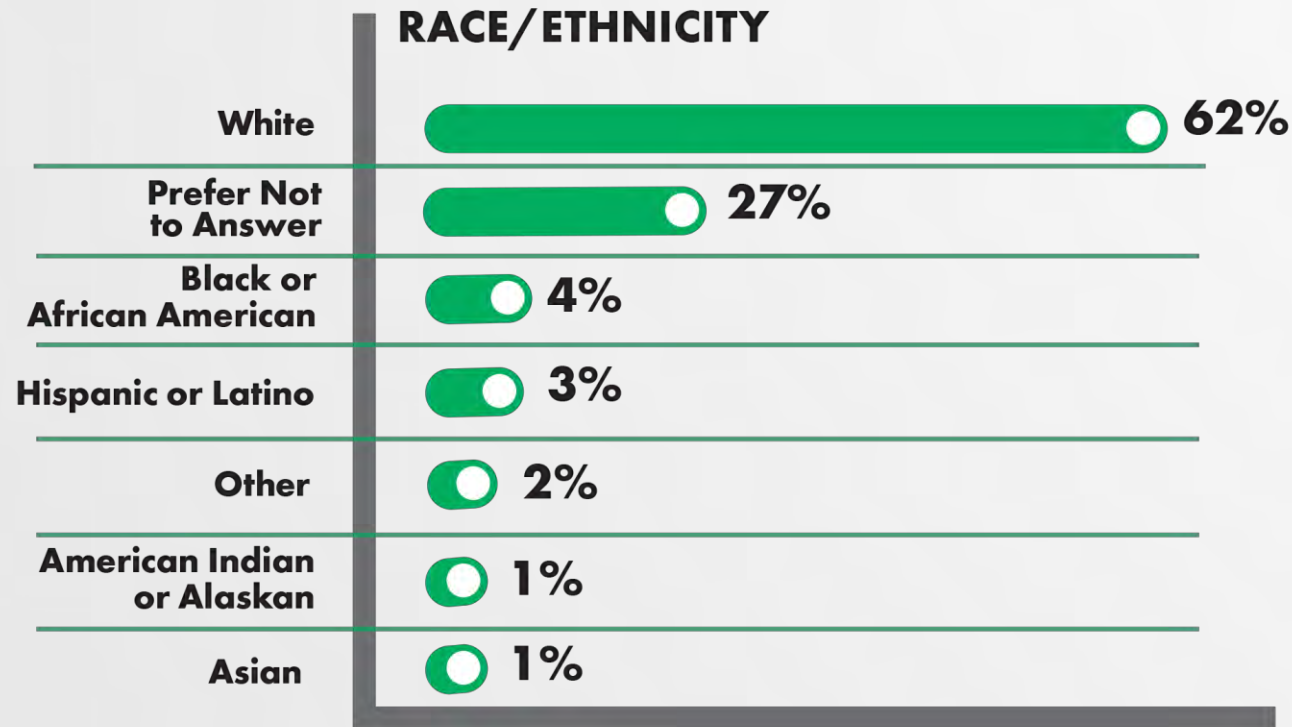
Live Yes! INSIGHTSSM

Results represent
a wide variety of
arthritis types

Live Yes!

INSIGHTSSM

Live Yes!
INSIGHTS **LIVE**



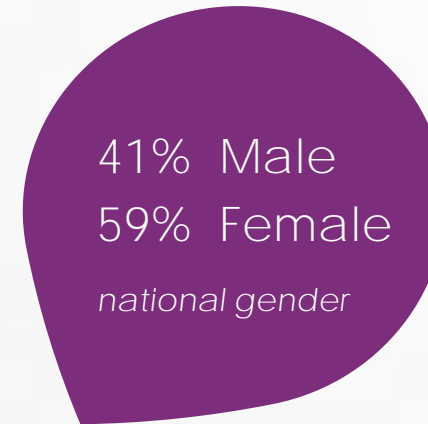
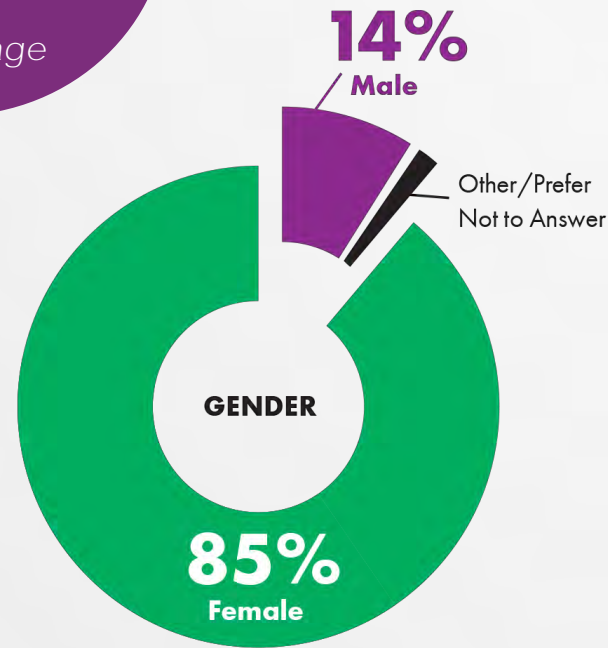
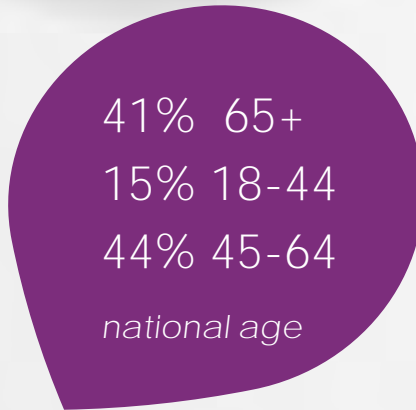
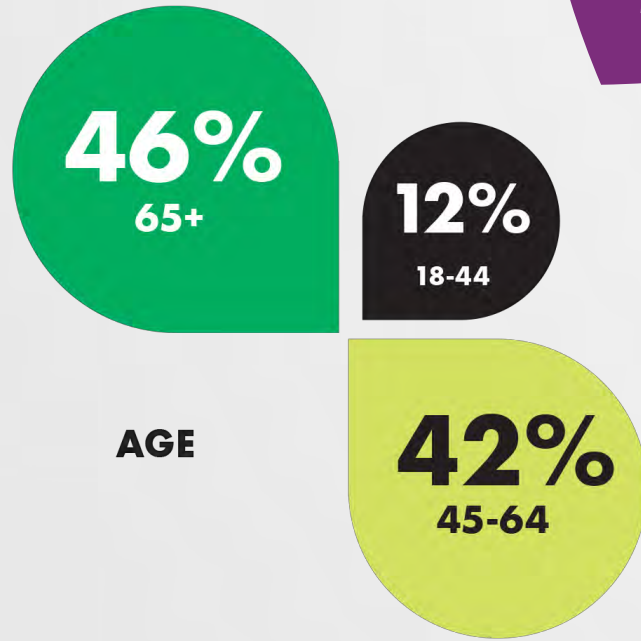
White: 76%
Black/African American: 11%
Hispanic/Latino: 8%
Multiple: 1%
American Indian/Alaska: 1%
Asian: 3%

national race/ethnicity

Live Yes!

INSIGHTSSM

Live Yes!
INSIGHTS **LIVE**





Key Findings

Impaired physical function. Chronic sleeplessness. Constant fatigue.

92% report that pain interferes with their day-to-day activities.

Reduced work abilities. Decreased family connectivity. Increased depression.

72% report having trouble doing all usual work.

Unmet needs. Disparities in care. Health care shortcomings.

Only 57% report receiving the help they need.

Disparities between our communities.

Wide-ranging differences between markets.

**PAIN CAN'T BE IGNORED. IT IS
AN INTENSE AND CONSTANT PRESENCE.**



**of patient responders
REPORTED PAIN** over the last
seven days — **with an
average pain score of
5 on a 10-point scale.**

What a “5” on the Pain Scale Means

Moderately strong pain. It can't be ignored for more than a few minutes, but with effort you still can manage to work or participate in some social activities.*

92%

**of patients reported
that pain interfered
with their day-to-
day activities.**

* Richards KL. The Pain Scale Chart: What it Really Means. ProHealth. Updated May 18, 2019. Retrieved from <https://www.prohealth.com/library/what-the-pain-scale-really-means-34982>

PAIN CORRUPTS PATIENTS' SLEEP AND UNLEASHES FATIGUE.



LESS THAN

1/3

slept well

in the past seven days.



73%

**reported feeling
fatigued** over the
past seven days.

Lupus patients are more
impacted at **88%**.

People in
**Oklahoma
and Maine**
are impacted even
more at **83%**.

Hispanics are
impacted more than
any other race at **78%**.

NOT LIVING THE LIFE THEY WANT IS TAKING AN EMOTIONAL TOLL.

2/3

said they
felt depressed

during the past seven days.



2/3

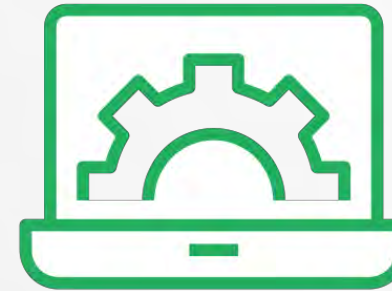
said they felt
anxiety or fear

during the past seven days.

PATIENTS HAVE TROUBLE WORKING.



reported having trouble
doing all usual work.
(including work at home)



Psoriatic Arthritis
patients are more
impacted at **79%.**

People in
Mississippi
are impacted even
more at **84%.**

**American
Indian or
Alaska Native**
are impacted more than
any other race at **81%.**

PAIN LIMITS ABILITY TO WALK.

Almost half of our community cannot walk easily.

43% reported that they
could not walk at all or had
major difficulty walking

for at least 15 minutes
during the past seven days.



Osteoarthritis

patients are more
impacted at **51%.**

People in
West Virginia
are impacted even
more at **58%.**

**African
Americans**
are impacted more
than any other race
at **54%.**

PATIENTS MISS OUT ON FAMILY ACTIVITIES.

67%

reported having trouble doing all the family activities they want to do.



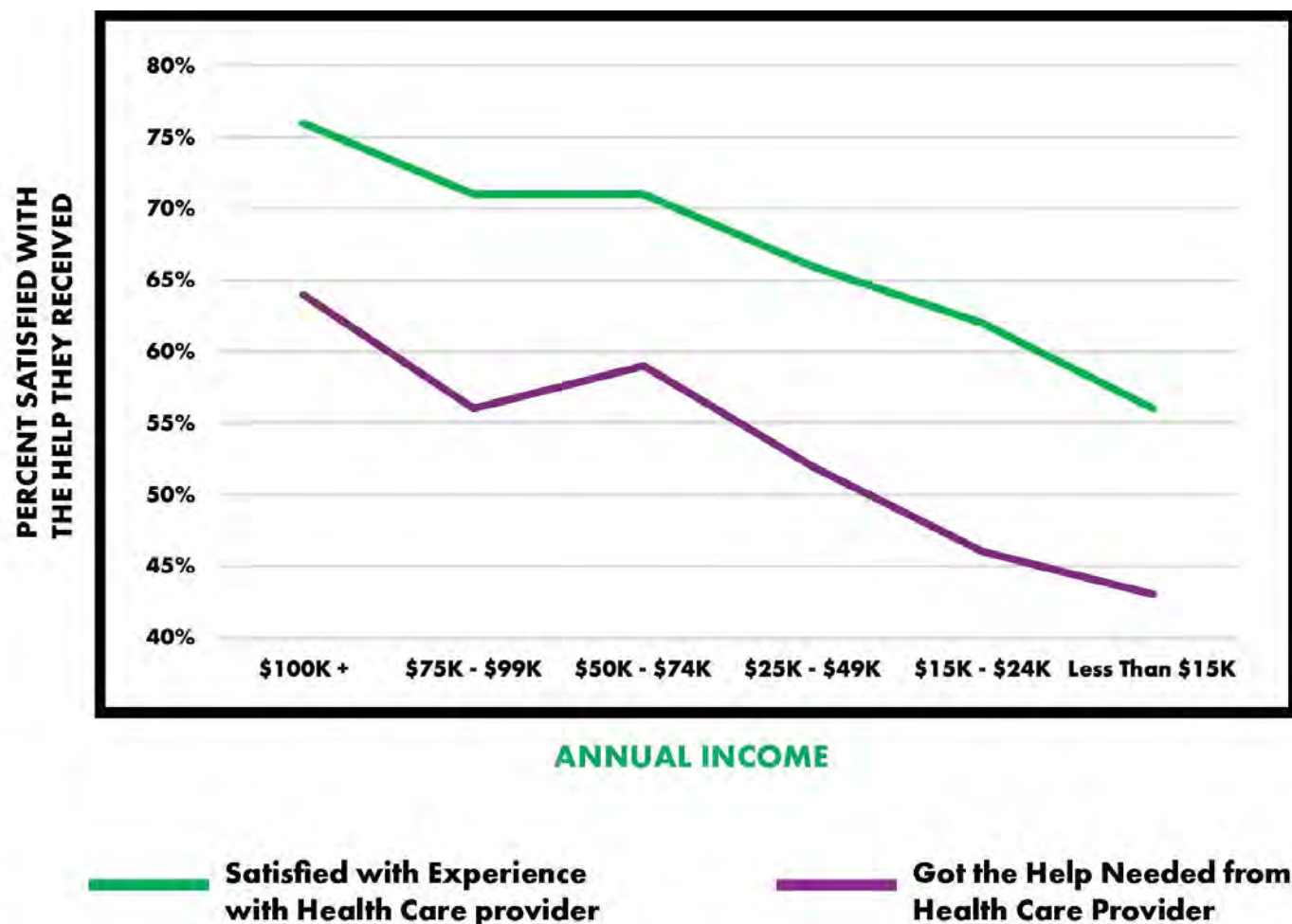
**Ankylosing
Spondylitis**

patients are more
impacted at **81%**.

People in
Alabama
are impacted even
more at **80%**.

**African
Americans** are
impacted more than
any other race at **73%**.

UNMET NEEDS. DISPARITIES IN HEALTH CARE.



93% of patients reported that it is extremely important to have the ability to talk to a professional to answer their questions.

YET ONLY

69% surveyed were satisfied with their experience.

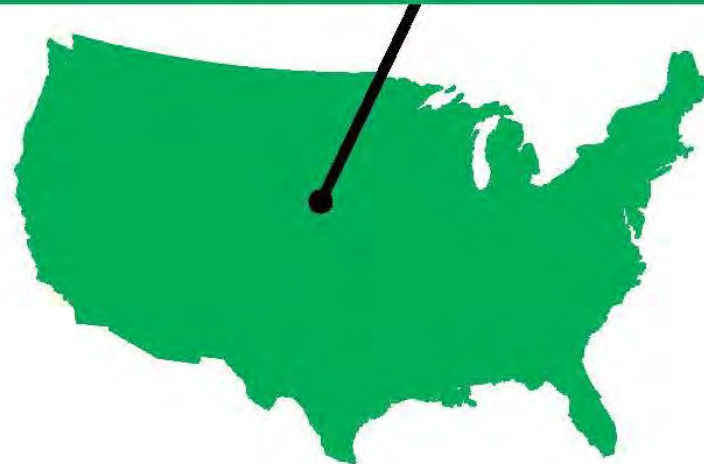
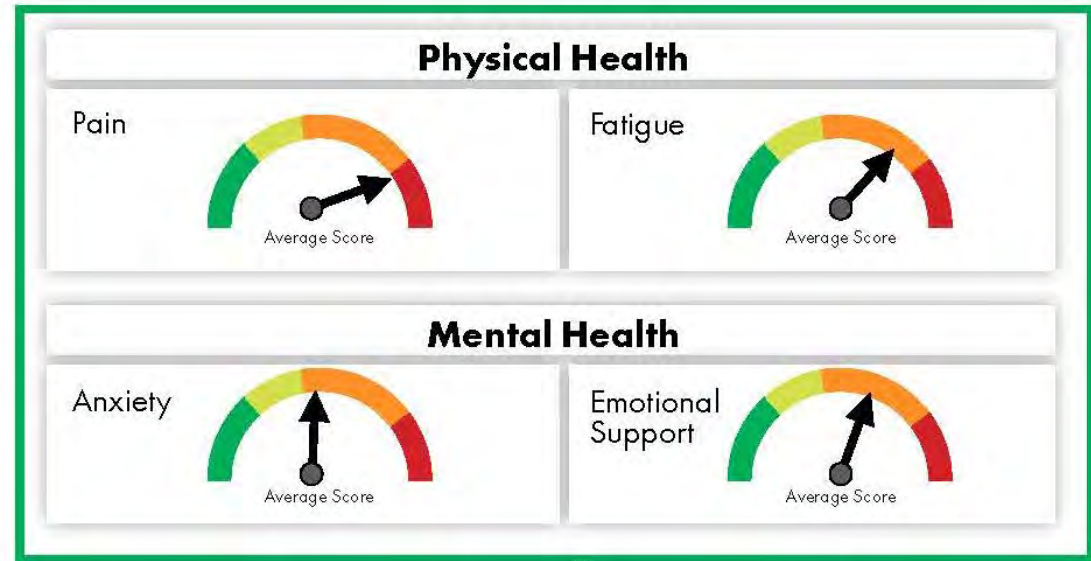
93% of patients reported that it is extremely important to get the help they need at their health care professional's appointment

YET ONLY

57% surveyed reported they got the help they needed.

Addressing Data Locally in Real-Time

Not only are results monitored at a national level, but the 70 local Arthritis Foundation markets across the country are making positive changes in their communities through tailored programs based on localized data.



As the leading health charity
focused on conquering
arthritis, our mandate is to
change lives while boldly
pursuing a cure.



What does this mean for patients?



Rapid Table Discussion:

- What are your reactions to the data?
- What does it mean for us here in NYC?
gaps we can close?
opportunities we can expand?

Facilitated Discussion:

- What can we DO with it?

Change is Needed Now



Closing and Action Steps

As you learned in tonight's program, **A Mandate for Action** highlights real-life arthritis patient experiences. The pain, hardship, isolation and marginalization of people with arthritis can no longer be ignored.

Review the commitment cards at your place and choose the answer that best describes how you feel about fighting for change with us!

Awareness

Commitment

Action

Outcome