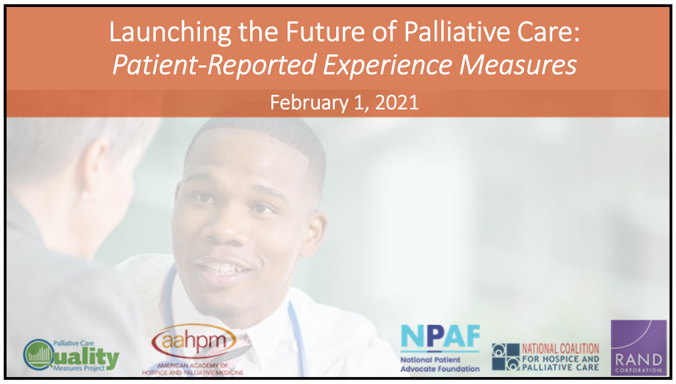
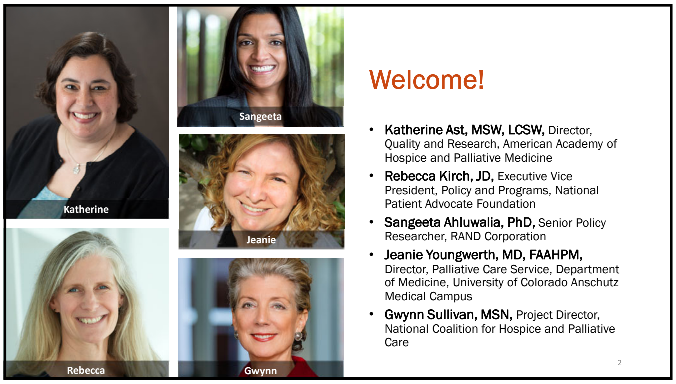


Launching the Future of Palliative Care: *Patient-Reported Experience Measures*

February 1, 2021

1



Welcome!

- **Katherine Ast, MSW, LCSW,** Director, Quality and Research, American Academy of Hospice and Palliative Medicine
- **Rebecca Kirch, JD,** Executive Vice President, Policy and Programs, National Patient Advocate Foundation
- **Sangeeta Ahluwalia, PhD,** Senior Policy Researcher, RAND Corporation
- **Jeanie Youngwerth, MD, FAAHPM,** Director, Palliative Care Service, Department of Medicine, University of Colorado Anschutz Medical Campus
- **Gwynn Sullivan, MSN,** Project Director, National Coalition for Hospice and Palliative Care

2

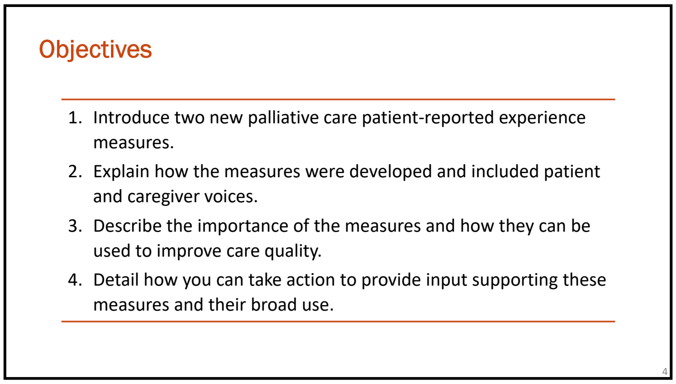
Guest Speakers

Sa'Brina Davis

NPAF National Patient Advocate Foundation Ambassadors

Faye Hollowell

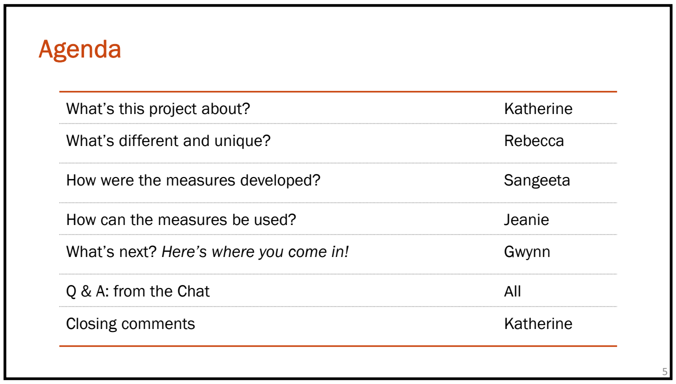
3



Objectives

1. Introduce two new palliative care patient-reported experience measures.
2. Explain how the measures were developed and included patient and caregiver voices.
3. Describe the importance of the measures and how they can be used to improve care quality.
4. Detail how you can take action to provide input supporting these measures and their broad use.

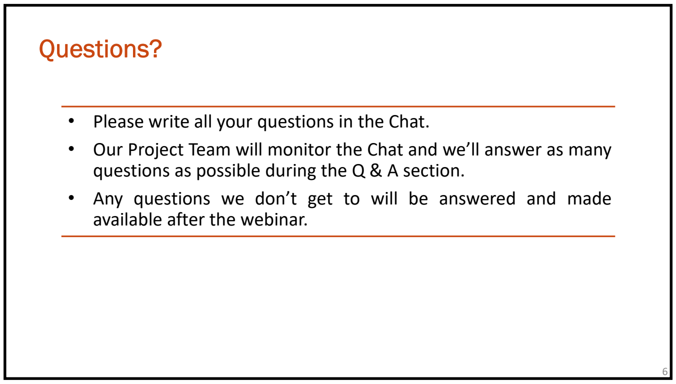
4



Agenda

What's this project about?	Katherine
What's different and unique?	Rebecca
How were the measures developed?	Sangeeta
How can the measures be used?	Jeanie
What's next? *Here's where you come in!*	Gwynn
Q & A: from the Chat	All
Closing comments	Katherine

5



Questions?

- Please write all your questions in the Chat.
- Our Project Team will monitor the Chat and we'll answer as many questions as possible during the Q & A section.
- Any questions we don't get to will be answered and made available after the webinar.

6

Polling Question #1

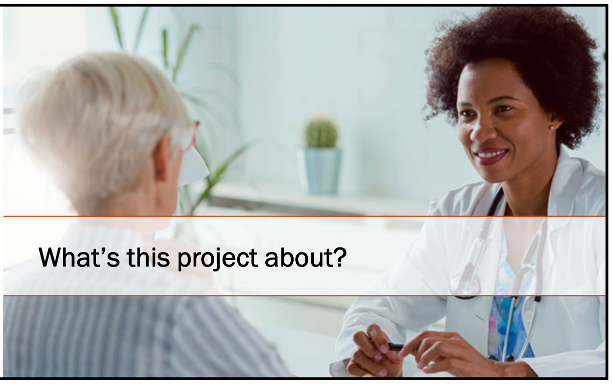
Who is in our audience?
(check all that applies)

- ☐ Patient/Family/Caregiver/Advocate
- ☐ Palliative Care Clinician/Team Member/Provider
- ☐ Other Health Care Professional/Administrator
- ☐ Representative from a National Organization/Association
- ☐ Representative from the Measurement Community

Polling Question #2

Have you previously provided input informing new health policy or quality measures?

- ☐ Yes
- ☐ No
- ☐ Not Sure



What's this project about?

Development of Palliative Care Measures

- **AAHPM**, in partnership with the **National Coalition for Hospice and Palliative Care** (Coalition) and the **RAND Corporation**, was awarded a three-year cooperative agreement from Centers for Medicare and Medicaid Services (CMS) to develop *patient-reported* quality measures for community-based palliative care. *(See more details on the project webpage.)*
- The measures are intended for use in **CMS's Quality Payment Program** to help support meeting patient needs by promoting quality improvement activities among providers.
- Through partnership with the **National Patient Advocate Foundation**, the project team sought and incorporated the perspectives of patients and caregivers as an essential aspect of developing quality measures that would be meaningful.

www.nationalcoalitionhpc.org/macra

Project Goal

Palliative Care Quality Measures Project

Develop two patient-reported quality measures of outpatient palliative care experience that matter to people receiving care.

- ➢ These new measures will be used by providers in CMS's **Merit-Based Incentive Payment System (MIPS)** and **Alternative Payment Models (APMs)** under the **Quality Payment Program (QPP)** created by MACRA.

Proposed Measures: Person-Centered Emphasis

Communication	Symptom Management
Palliative care outpatients' experience of *feeling heard and understood*	Palliative care outpatients' experience of *receiving desired help for pain*

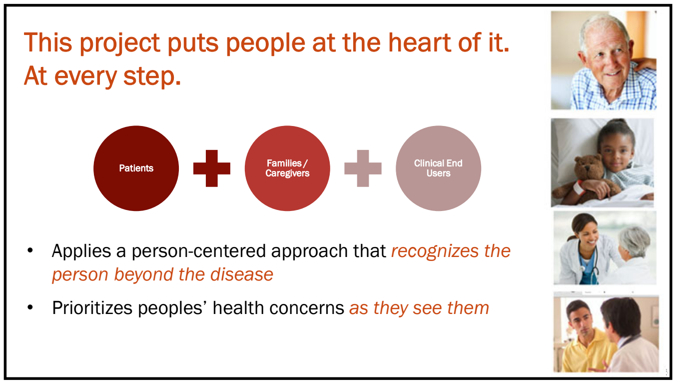
Why these particular measures?

- Palliative care field has prioritized these measure concepts as essential aspects of quality care delivery.
- Measures address significant gaps in care, namely in nuanced symptom management (pain) and skilled communication that is meaningful.
- Patient experience measures are largely lacking (except for the CAHPS survey, which some say is long and burdensome).
- Providers need quality measures for accountability that align with essential skills that patients, caregivers and family members agree are important.
- New alternative payment models (APMs) that prioritize “value” need a measurable way to distinguish good performance from poor performance.

13

What’s different and unique?

14



This project puts people at the heart of it. At every step.

- Applies a person-centered approach that *recognizes the person beyond the disease*
- Prioritizes peoples’ health concerns *as they see them*

15

Innovative and Inclusive Project Plan

- Explicitly makes patients, caregivers and family *proactive parts of the team* – for care quality and accountability
- Recognizes that peoples’ challenges and care *needs change over time*
- Targets outpatient setting, but approach is *applicable in ALL care settings* for quality improvement initiatives that meet peoples’ needs

16

The Power of Skilled Communication: Making Trusted Care Happen

Talk about the care that matters

Tell the people that matter

Knowing what’s important to patients and caregivers is paramount.

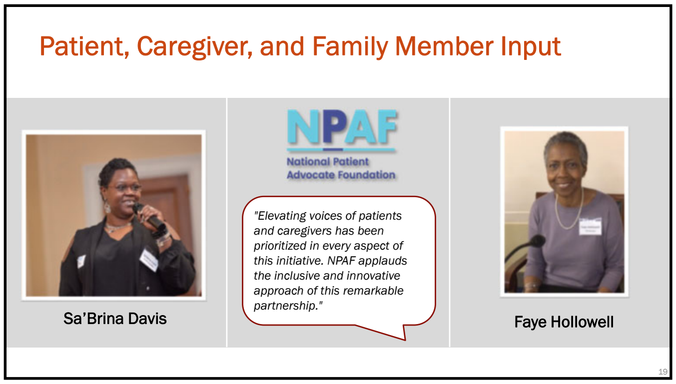
They want:

1) Understandable, accurate information
2) Personalized to meet their pressing needs and concerns
3) Engagement as partners
4) Care that matches their priorities

17

What matters to patients is *essential expertise* they must be invited to share. Early and often.

18



Patient, Caregiver, and Family Member Input

Sa'Brina Davis

NPAF
National Patient Advocate Foundation

"Elevating voices of patients and caregivers has been prioritized in every aspect of this initiative. NPAF applauds the inclusive and innovative approach of this remarkable partnership."

Faye Hollowell

19

Sa'Brina Davis, NPAF Volunteer

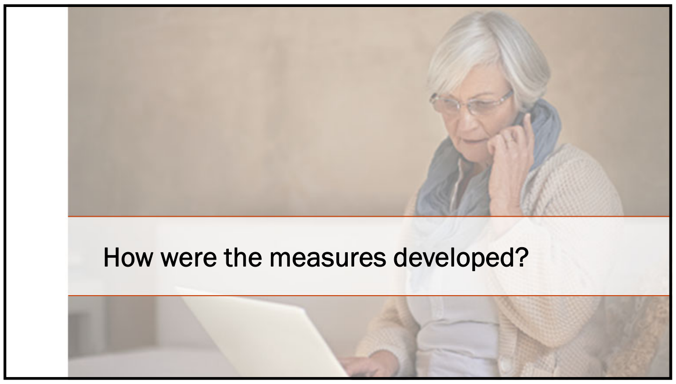
NPAF
National Patient Advocate Foundation

20

Faye Hollowell, NPAF Volunteer

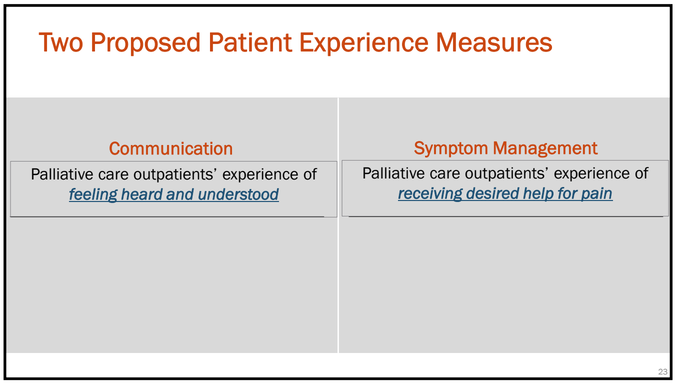
NPAF
National Patient Advocate Foundation

21



How were the measures developed?

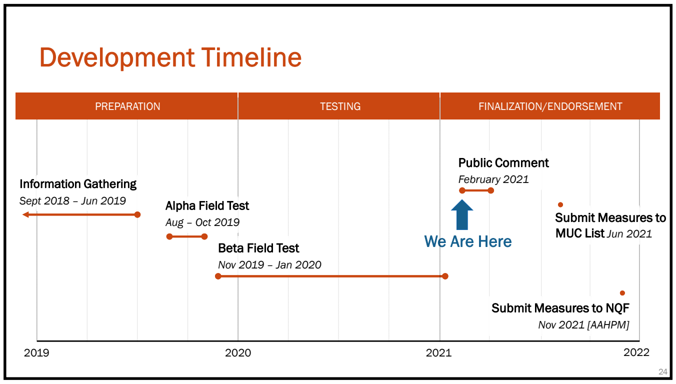
22



Two Proposed Patient Experience Measures

Communication	Symptom Management
Palliative care outpatients' experience of *feeling heard and understood*	Palliative care outpatients' experience of *receiving desired help for pain*

23



Development Timeline

PREPARATION | TESTING | FINALIZATION/ENDORSEMENT

Information Gathering
Sept 2018 – Jun 2019

Alpha Field Test
Aug – Oct 2019

Beta Field Test
Nov 2019 – Jan 2020

Public Comment
February 2021

We Are Here

Submit Measures to MUC List *Jun 2021*

Submit Measures to NQF
Nov 2021 [AAHPM]

24

Information Gathering

- Literature scan
- Focus groups with palliative care providers
- Interviews with patients and caregivers
- Meetings with technical expert panels
- Cognitive testing with patients and caregivers

Alpha Field Test

- Goal was to better understand capabilities of fielding a patient survey and to prepare for the national field test (beta)
- Tested across 300 patients and 5 outpatient palliative care programs
- Results informed decisions about eligibility criteria, survey procedures and response rates estimates

National Beta Field Test

- Used a web-to-mail-to-phone survey design
- Surveys sent to over 8,800 adult patients receiving care from 43 outpatient palliative care programs across the U.S.
- As of mid-December 2020, 3,600 surveys returned
- Data from these surveys are being used to establish the reliability and validity of the two proposed measures and to finalize measure specifications

Heard and Understood Measure

The Heard and Understood measure is comprised of four survey questions:

“Thinking about your overall experience with this provider and team in the last 6 months, how true are the following statements?”

- ➢ I felt heard and understood by this provider and team.
- ➢ I felt this provider and team put my best interests first when making recommendations about my care.
- ➢ I felt this provider and team saw me as a person, not just someone with a medical problem.
- ➢ I felt this provider and team understood what is important to me in my life.

Heard and Understood Measure

Preliminary analyses show:

- Most patients rate their provider and team positively (69%) however measure performance varies between programs (variance in average program scores=0.018)
- Approximately 115 returned surveys would be needed per program, per year, to reliably distinguish measure performance between programs

Help Wanted for Pain Measure

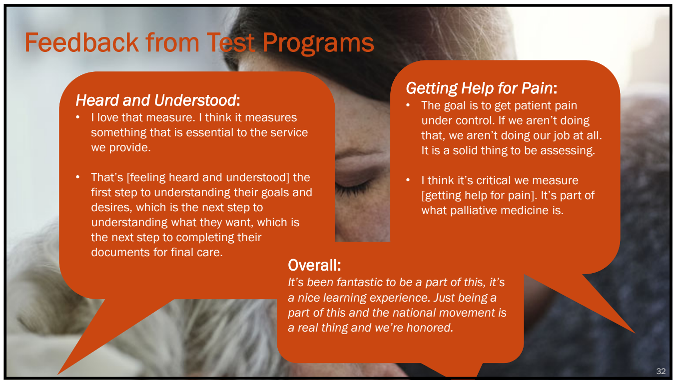
The Help Wanted for Pain measure is constructed using responses from three survey questions:

- ➢ “In the last 6 months, have you ever had pain?“
- ➢ “In the last 6 months, did you want help from this provider and team for this pain?”
- ➢ **“In the last 6 months, did you get as much help as you wanted for your pain from this provider and team?”**

Help Wanted for Pain Measure

- Preliminary analyses show a high prevalence of pain among patients and wanting help for pain from palliative care providers and teams.
- The majority of patients reported “definitely” (81%) or “somewhat” (16%) getting as much help as they wanted for their pain.
- Performance varied between programs (variance in average program scores=0.049).
- Approximately 55 returned surveys would be needed per program, per year, to reliably distinguish measure performance between programs.

31



Feedback from Test Programs

***Heard and Understood*:**
- I love that measure. I think it measures something that is essential to the service we provide.
- That’s [feeling heard and understood] the first step to understanding their goals and desires, which is the next step to understanding what they want, which is the next step to completing their documents for final care.

***Getting Help for Pain*:**
- The goal is to get patient pain under control. If we aren’t doing that, we aren’t doing our job at all. It is a solid thing to be assessing.
- I think it’s critical we measure [getting help for pain]. It’s part of what palliative medicine is.

Overall:
It’s been fantastic to be a part of this, it’s a nice learning experience. Just being a part of this and the national movement is a real thing and we’re honored.

32

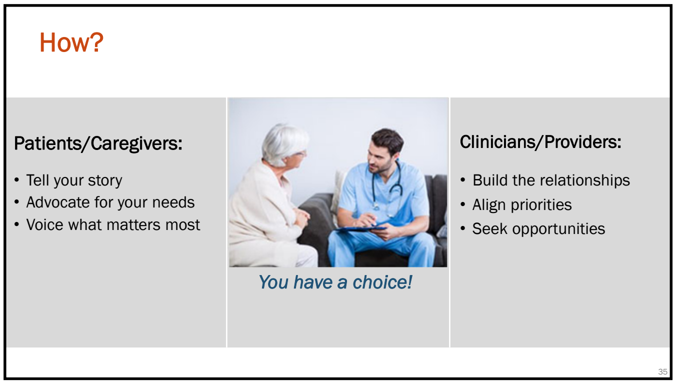
How can the measures be used?

33

Why?

- Meet the needs of people living with serious illness
- Work together as a team
- Build public demand for palliative care

34



How?

Patients/Caregivers:
- Tell your story
- Advocate for your needs
- Voice what matters most

You have a choice!

Clinicians/Providers:
- Build the relationships
- Align priorities
- Seek opportunities

35

The Ask

We can make a difference together.

Please give your support of the measures during the public comment.

36

What's next? *Here's where you come in!*

Opportunity #1

Support Patient-Centered Care

- ✓ Clinicians/Providers/Professionals: *Give* quality care based on patients' unique needs!
- ✓ Patients/Families/Caregivers: *Receive* quality care base on your unique needs!

Opportunity #2

Give Feedback via Public Comment

Easy three-step process:

1. Click HERE to answer survey
2. Choose your category:
   - Clinician/Provider/Professional
   - Patient/Family/Caregiver
3. Answer seven questions (*estimated time is only 2-5 minutes*)

Public Comment Questions

Clinician/Provider/Professional

1. How likely would you choose to report on these measures?
2. Which measure(s) would you elect to report?
3. How feasible would it be to implement these measures?
4. How likely are you to use Heard and Understood measure to improve your practice and/or the care you provide?
5. How likely are you to use Help Wanted for Pain measure to improve your practice and/or the care you provide?
6. Please indicate your support (for each measure).

Patient/Family/Caregiver

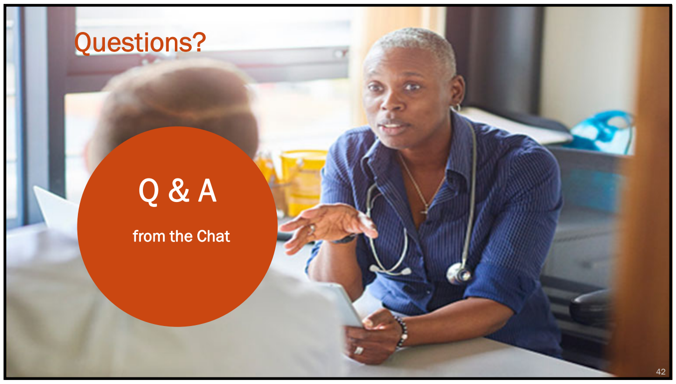
1. Do you think the Heard and Understood measure captures important information?
2. What could a health care team do to help you and other patients feel more heard and understood?
3. Do you think the Help Wanted for Pain measure captures important information?
4. What could a health care team do to help you and other patients get the help you want for pain?
5. How likely would you be to complete a survey about your experience with your health care provider and team?
6. Please indicate your support (for each measure).

Opportunity #3

Help us get the word out!

Stay Informed

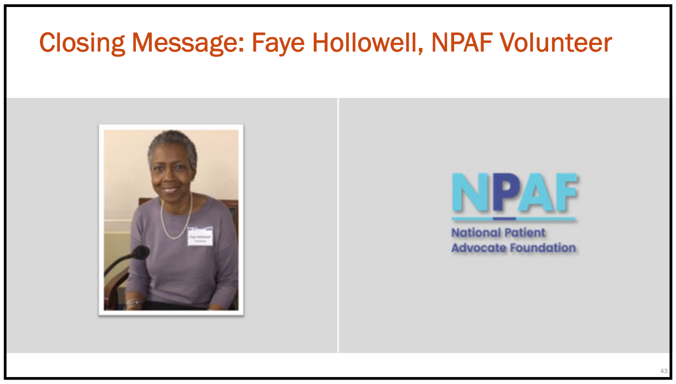
- ➢See project updates: www.nationalcoalitionhpc.org/macra
- ➢Follow us on Twitter: @coalitionhpc
- ➢Contact us: macra@nationalcoalitionhpc.org



Questions?

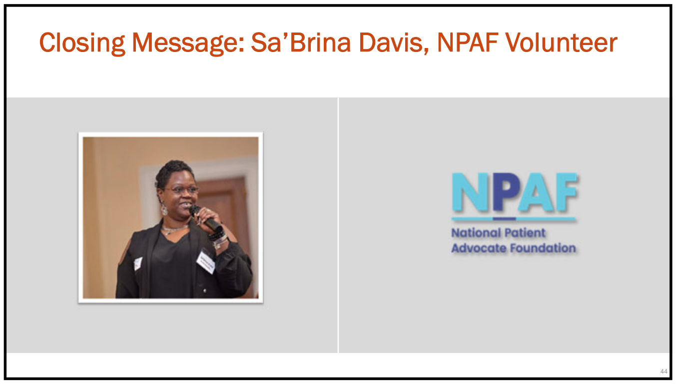
Q & A

from the Chat



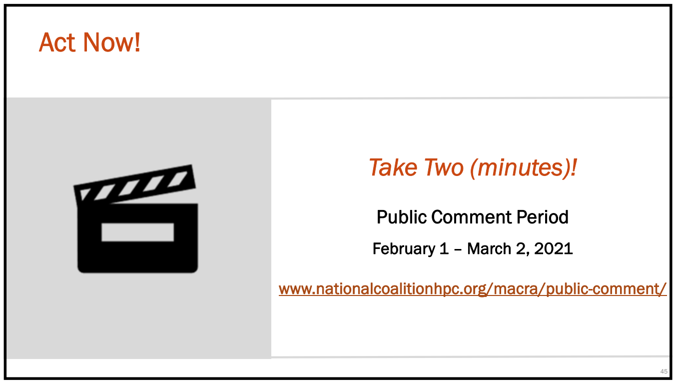
Closing Message: Faye Hollowell, NPAF Volunteer

NPAF
National Patient
Advocate Foundation



Closing Message: Sa’Brina Davis, NPAF Volunteer

NPAF
National Patient
Advocate Foundation



Act Now!

Take Two (minutes)!

Public Comment Period

February 1 – March 2, 2021

www.nationalcoalitionhpc.org/macra/public-comment/

Thank you!

www.nationalcoalitionhpc.org/macra