Can We Talk?

Advocating to Put People at the Heart of Health Care

Presented by
Melissa Williams and Sheila Stickel,
National Patient Advocate Foundation

Speakers

Melissa Williams, MPH
Manager of Healthcare Policy and Advocacy
Staunton, Virginia

Sheila Stickel
Field Director, Western States
Seattle, Washington

Who We Are

National Patient Advocate Foundation (NPAF) represents the voices of patients and caregivers coping with serious and chronic illnesses nationwide as the advocacy affiliate of Patient Advocate Foundation (PAF).

- **PAF provides direct case management, financial support, and educational services** for primarily **low-income patients and caregivers** experiencing financial hardships due to illnesses.

- **NPAF** develops person-centered policies and drives evidence-based solutions promoting **equitable access to affordable, quality health care** at federal, state, and local levels through advocacy action and public and private partnerships.

What is person-centered care?

Credit: Shutterstock

Putting People at the Heart of Health Care

Why "Person-Centered" Care?

"Patient-Centered" focuses on interactions in visits to manage diseases.

Person-centered care *recognizes patients' health problems as they see them.*

- Focuses on the *whole person*
- Includes caregivers in the unit of care
- Provides foundation for better recognition of health problems and needs over time
- Facilitates appropriate care for these needs in the context of other needs

B. Starfield. Is Patient-Centered Care the Same as Person-Focused Care?
The Permanente Journal 2011; 5(2): 6369.

What matters to people?

How much is this going to cost?

Is that covered?

Are you in-network or out-of-network?

I don’t want my illness to financially ruin me.

Will I still be able to work?

How can I get to my appointment?

Who will help / teach me?

How can I control the pain, so that I can still do the things I love?

JOURNAL OF CLINICAL PATHWAYS®
THE FOUNDATION OF VALUE-BASED CARE

Palliative Care: The "Miracle Drug" Still Missing in Many Clinical Pathways

Rebecca Kirch, JD; Caitlin Donovan; Alan Balch, PhD—Column Editor

If palliative care were a drug, we would be holding hearings on Capitol Hill right now, demanding to know why everyone does not have access to its benefits. We would be writing think pieces, positing ways to bring down palliative care costs; we would be pushing the Food and Drug Administration for fast-track approval. We would be writing of the ways in which we should be incorporating palliative care into clinical pathways.

Instead, when most patients hear "palliative care," they either do not know what it is, or they think it means care for the dying. Likewise, clinicians often associate palliative care with the end of life or "what to do when there is nothing left to do."

What is Palliative Care?

- Team-based medical care focused on **quality of life for the patient and family** that provides relief from the pain, symptoms, and stresses of serious illness
- Appropriate at **any age and disease stage**
- Provided along with curative treatment as an **added layer of support**

What is the Issue?

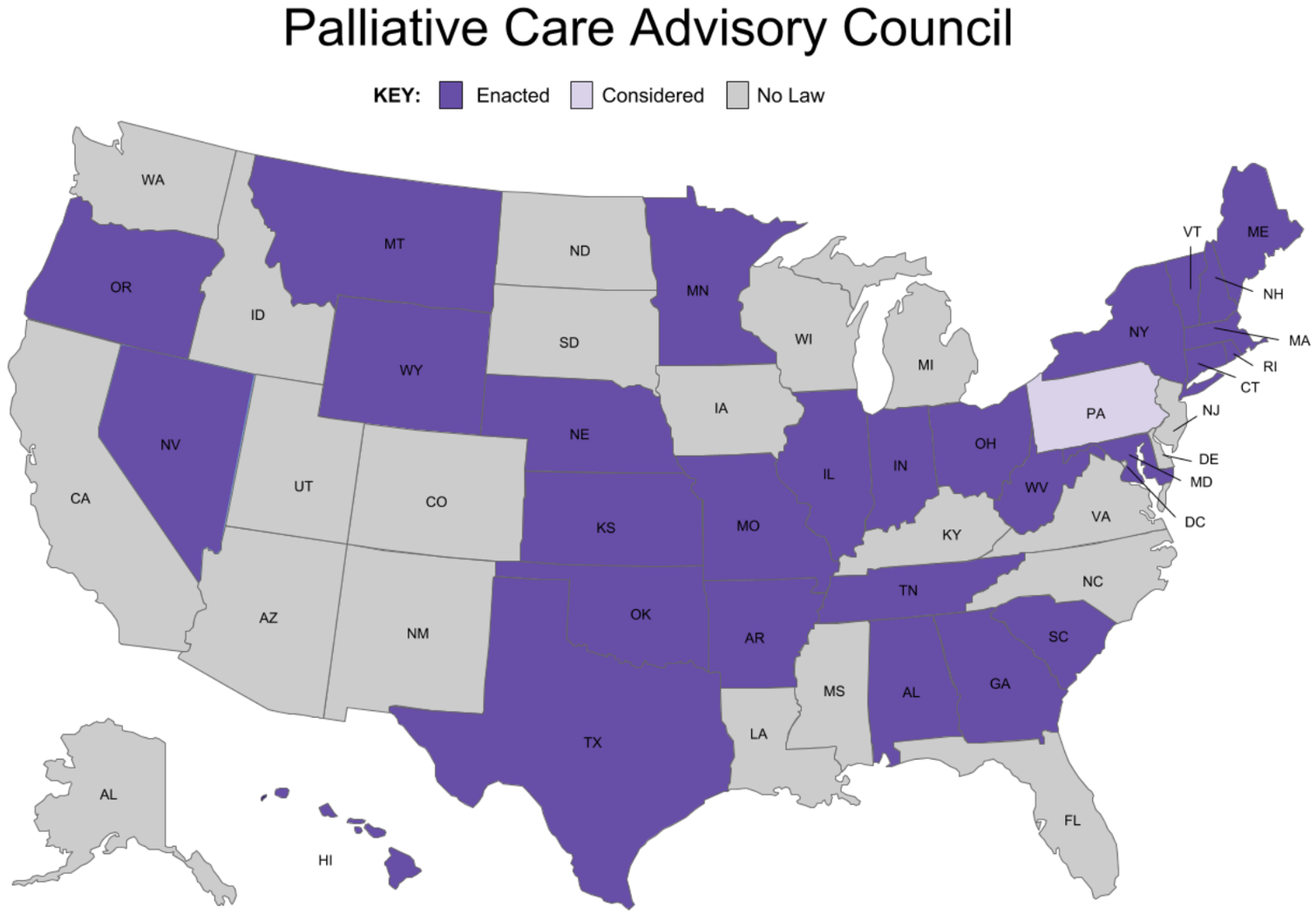
- **Gaps persist in** professional, public, and policymaker **understanding** about **the benefits of providing palliative care** as part of disease-directed treatment throughout the illness experience.

- **Access to palliative care is limited** — particularly in community settings.

- **The specialist palliative care workforce is in short supply** to reach all patients and families in need.

Solutions

- **Federal:** Palliative Care and Hospice Education and Training Act (PCHETA)
- **State:** Palliative Care Advisory Councils
- **Local:** You!



What Can YOU Do?

How can we put patient and caregiver voices at the heart of health delivery reform?

Educate. Energize. Engage

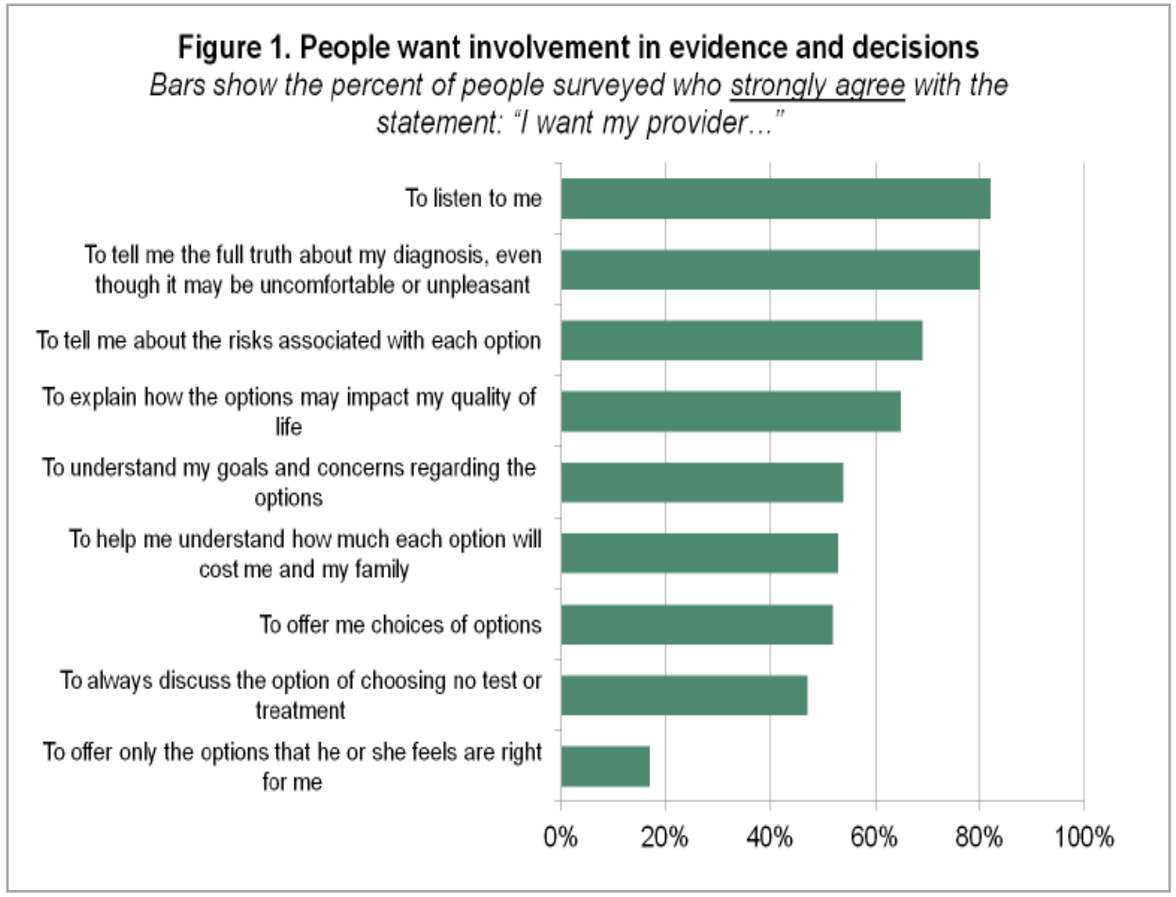
Great Conversations Start with Hello

What is Hello

- A conversation game created by COMMON PRACTICE (commonpractice.com).
- It is an easy, non-threatening way to start a conversation with your family and friends about ***what matters most to you***. It helps transform anxiety about dying into ***conversations about living***.

Background

When it comes to their health care, **people want involvement in evidence and decisions**.



People want to know:

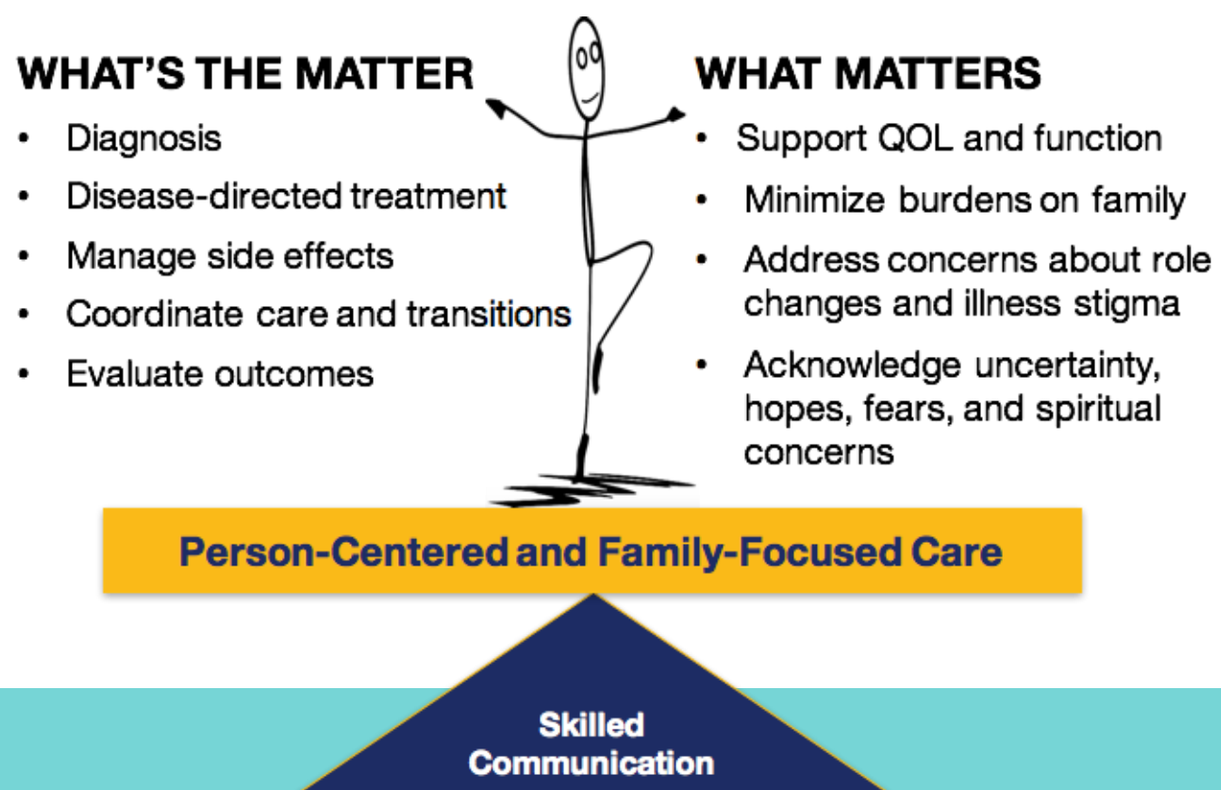
- The full **truth**,
- The **risks** involved,
- The impact on **quality of life**,
- And that their **goals and concerns** are understood

Findings from Institute of Medicine national survey of 1,068 US adults who had seen one health care provider in previous year, reported in 2013 Quality Cancer Care report: Charting a New Course for a System in Crisis.

Background

- THE ISSUE: Our current health care system focuses more on the disease (*what's the matter)*, instead of the needs and the quality of life (QOL) of patients and families (*what matters).*

- THE SOLUTION: We need to reorient our health care system so it focuses on **both**. To do that, we need to provide patients, families, and health care professionals the **skills to be better communicators**.



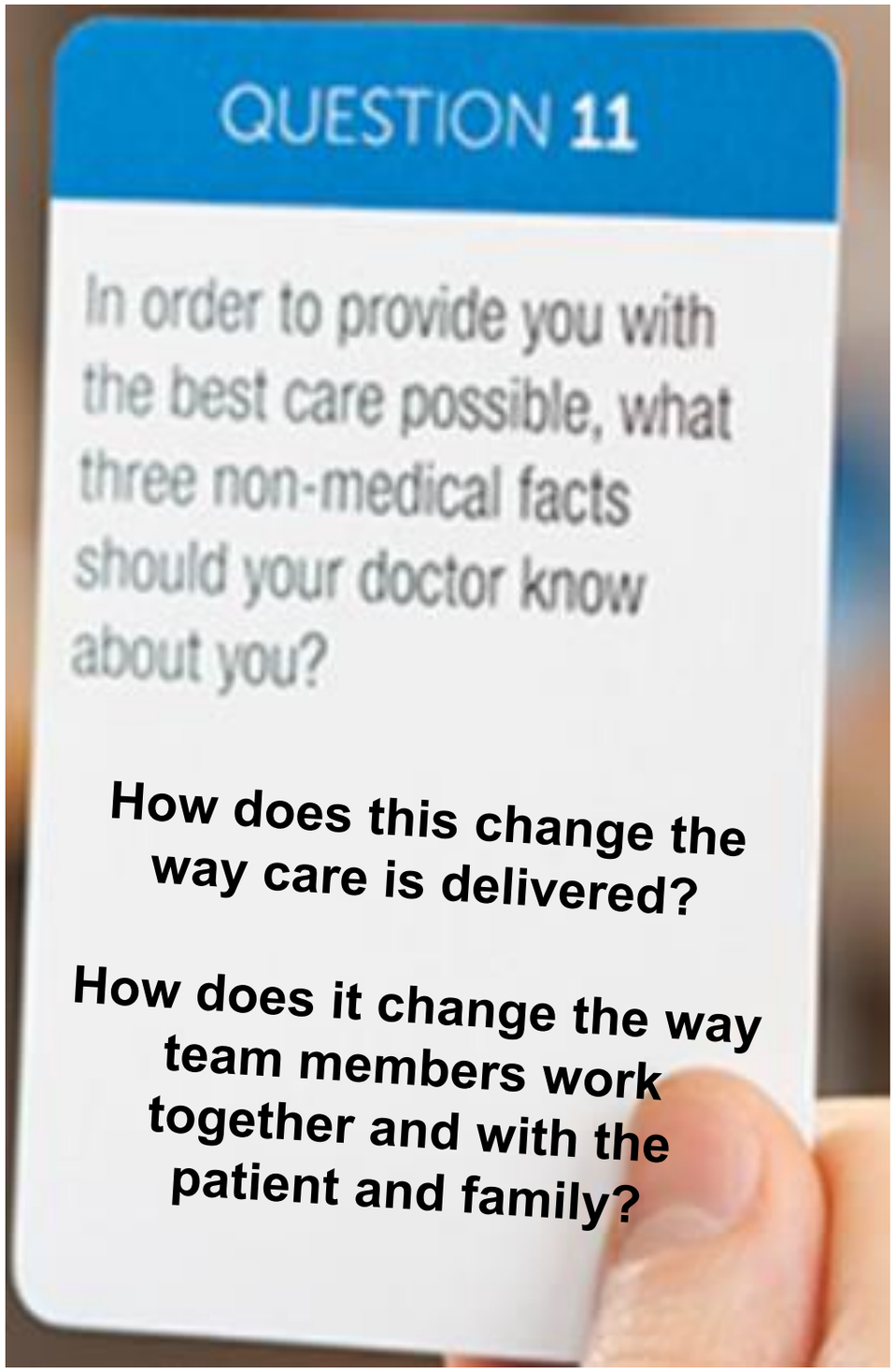
How Can Hello Help

Hello gives **people** the words to use.

Hello fosters communication with healthcare professionals and family members that help match treatments with personal goals.

Imagine the difference it could make for patients and caregivers if everyone on the care team knows …

- Something about them as **a person** — not just as someone with a medical problem
- What problems are **most important** to them



As a Patient, Family Caregiver or Community Advocate, How Can I Use Hello?

Play the game with your loved ones.

Share the experience with others.

Let’s Play

Hello

Join Our Grassroots!

If you're interested in becoming an NPAF Grassroots Volunteer or are interested in playing **Hello** in your community, visit www.npaf.org and click **Get Involved**.

Hello Toolkit

NPAF
National Patient Advocate Foundation

Great Conversations Start with

Hello

Hello is a conversation game created by Common Practice. It is a non-threatening way to have serious conversations with friends, family and your health care team about what matters to you and we think it's a great tool to help people understand the importance of person-centered care. The best way to learn about the game is to play and experience it for yourself, but you can see videos and more about Hello on the Common Practice website.

In this toolkit, you will find instructions on how you can use Hello as a way to educate your family, friends and community about person-centered care. We've outlined three different ways to use "Hello" no matter where you live or how much free time you have. In addition, you will also find in this toolkit:

- Instructions: How to Use Hello
- Frequently Asked Questions
- Hello Needs Assessment
- Event Request Form

Once you've played Hello, we would love to hear about your experience! We will also appreciate your input about how you can bring Hello right to your communities. In the meantime, if you have any questions about Hello and what you as can do as an advocate for NPAF, please contact Donna Guinn at donnag.kaufman@npaf.org.

Patient Congress 2017

Questions?

Thank you!

PLEASE CONTACT US:

Sheila.Stickel@npaf.org

Melissa.Williams@npaf.org