

The Power of Patient Stories

RACHEL GROB, MA, PhD
DIRECTOR OF NATIONAL INITIATIVES
CLINICAL PROFESSOR
SCIENTIST

CAHPS Webcast
5/12/22

Let me tell you a story...

Stories
powerfully
complement
CAHPS
surveys

Stories are a
tool for quality
improvement

Stories are a
tool for public
reporting

Stories about
many different
kinds of
experience can
be rigorously
elicited

... about the power of stories...



... with **COVID** as a main character.

July 2020 – Dec, 2021

surveys: 1,026
comments: 2,100

THREE Distinct Areas of Added Value

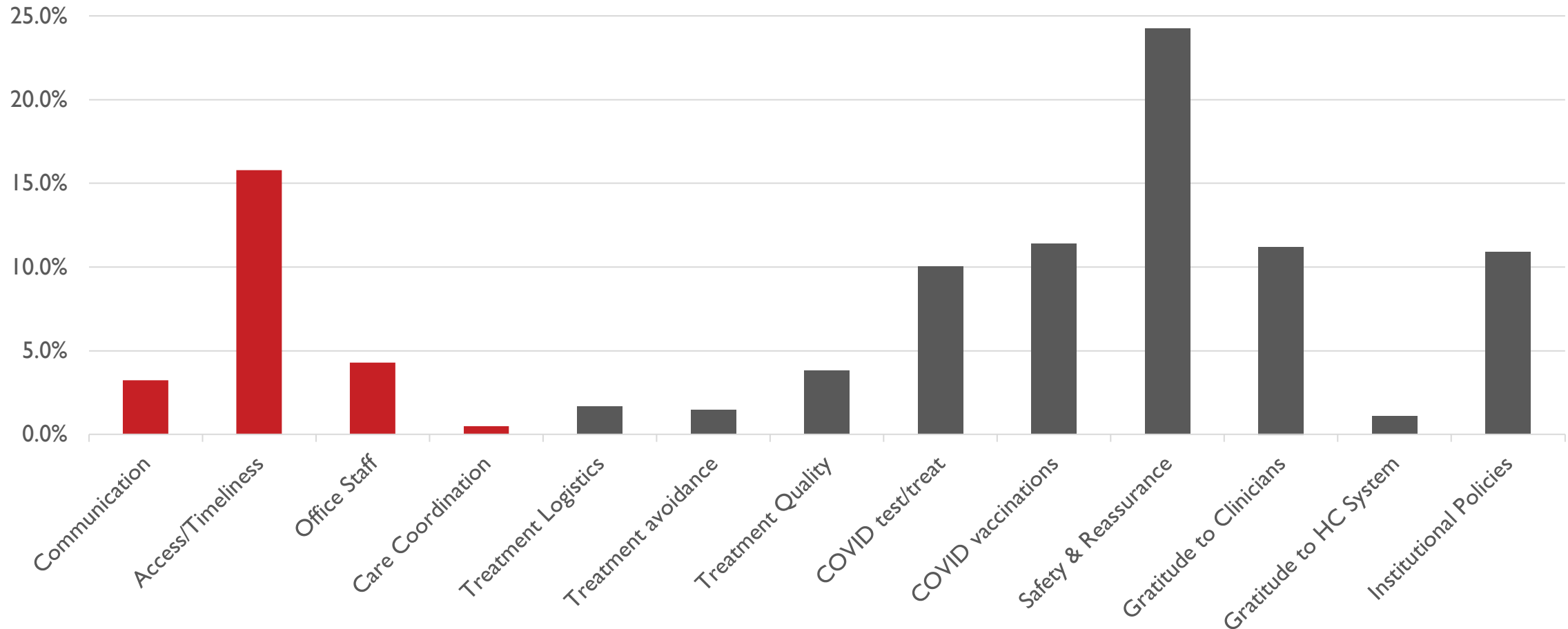
- Provide concrete and actionable examples of aspects of care already being measured (INTEGRAL)
- Highlight elements of composites that are not being directly measured (PROXIMAL)
- Highlight domains of care that are important to patients but not included on CG-CAHPS surveys (DISTAL)

THE
MILBANK QUARTERLY
A MULTIDISCIPLINARY JOURNAL OF POPULATION HEALTH AND HEALTH POLICY

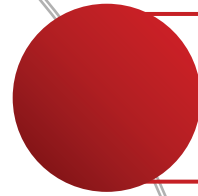
What Words Convey: The Potential for
Patient Narratives to Inform Quality
Improvement

Frequency of COVID Comments, All Domains

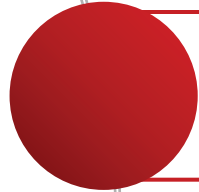
Percent of All Surveys



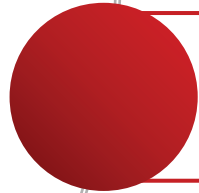
CG CAHPS Domains



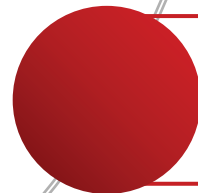
Communication



Access



Office Staff



Care coordination

Integral: Communication

Discussing COVID

Providers may spend less time, but it's okay

Masks can make communication difficult

Providers remain responsive and kind despite pandemic



Proximal

Communication:
Reassuring,
insufficient, useful



Proximal

Communication:
Reassuring,
insufficient, useful

Access: Working,
difficult, delayed,
necessary, hard

Proximal

Proximal

Communication:
Reassuring,
insufficient, useful

Access: Working,
difficult, delayed,
necessary, hard

Office Staff: Not
physically present,
compassionate

Proximal

Communication:
Reassuring,
insufficient, useful

Coordination: For
COVID testing, for
vaccines, using
remote modalities

Access: Working,
difficult, delayed,
necessary, hard

Office Staff: Not
physically present,
compassionate

Gratitude for excellent care

Understand and accept changes in care

Empathy with providers

Distal:
Grace for
Providers

Getting guidance

Post COVID symptoms

Discerning when to go to hospital

Empathy about COVID

Distal:
COVID Care

Clinic Practices and Organization

Provider Practices

Exposure to Other Patients

Distal:
Safety

Care has improved

Institution should follow/enforce its own rules

Institution should create better rules

Public policies are affecting care

Distal:
Changing
Institutional
Policies

CAHPS: Blending science and stories...

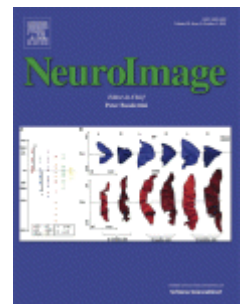
Using And Misusing Anecdote In Policy Making

[John E. McDonough](#)

HealthAffairs

Amygdala and heart rate variability responses from listening to emotionally intense parts of a story

Mikkel Wallentin ^{a, b}  , Andreas Højlund Nielsen ^{a, c}, Peter Vuust ^{a, d}, Anders Dohn ^{a, d}, Andreas Roepstorff ^{a, c},
Torben Ellegaard Lund ^a



... because stories are essential.

“Narrative imagining — story — is the fundamental instrument of thought. Rational capacities depend upon it. It is our chief means of looking into the future, or predicting, of planning, and of explaining.”

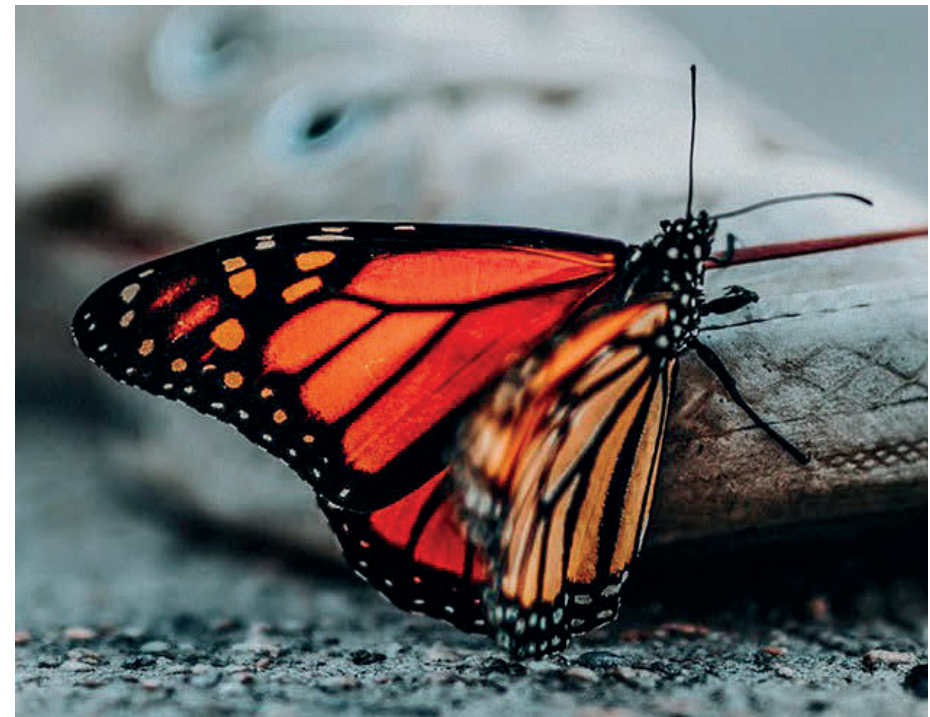
- *Mark Turner, cognitive scientist, linguist & author*

“In the future, your survey should account for Telehealth visits... since the onslaught of the COVID-19 Pandemic. Accounting for such non-physical visits will necessarily change certain questions in the survey....” – *NIS respondent*

“Free text, narrative feedback were preferred to checkboxes, surveys and patient satisfaction style ratings.”

“Everything must be made as simple as possible. But not simpler.”

- *Albert Einstein*



Acknowledgements

New York Presbyterian

CAHPS Narratives Team

Patients providing feedback using NIS

Emily Warne