## The Power of Patient Perspectives

### Compassion in Action Webinar Series

February 12, 2019



#### **Moderator**



Stephanie Adler Yuan
Director, Education & Training
The Schwartz Center for Compassionate Healthcare



#### **Audience Reminders**

This webinar is funded in part by a donation in memory of Julian and Eunice Cohen.

You may submit a question by typing it into the Question and Answer pane at the right of your screen at any time.

We value your feedback! Please complete our electronic survey following the webinar.



## Host



Beth Lown, MD

Medical Director

The Schwartz Center for Compassionate Healthcare







## **Today's Speaker**



Gregory Makoul, PhD MS
Founder and CEO
PatientWisdom, Inc.

Professor of Medicine | UConn School of Medicine Faculty | Yale School of Medicine Editor-in-Chief | Patient-Centered Innovation (special section of Patient Education & Counseling)



#### **Overview**

#### Goals

- Recognize how patient stories can inform health professional education and serve as a touchstone for practice
- Describe how finding out what matters to patients can improve the experience and delivery of care in everyday practice

#### Highlights

- Xs and Oh! Patient-centered care sounds simple, but simple things can be hard
- Patient Narrative Videos Focusing trainees, faculty, staff, and leadership on the illness experience
- Concepts of Health An example of how patient perspectives broaden professional perspectives
- Patient-Generated Contextual Information Bringing 'what matters' to everyday clinical practice

#### **Disclosures**

Greg is Founder and CEO of Patient Wisdom, Inc. and will show screenshots to illustrate one way
of integrating 'what matters to patients' into the workflow.



## Reality check: Patient-centered care sounds simple

Respect patients as people.

Pay attention to patient perspectives.



Simple things can be hard. Solutions have to be easy.



#### Xs and Oh!

#### FROM THE OXFORD STUDY CODEBOOK

IF, DURING A PARTICULAR TURN, THE MD OR PT IS NOT TALKING ABOUT A PROBLEM OR SOLUTION, WE WILL NOT CODE THAT TURN. INSTEAD, MARK AN "X" ON THE APPROPRIATE LINE.

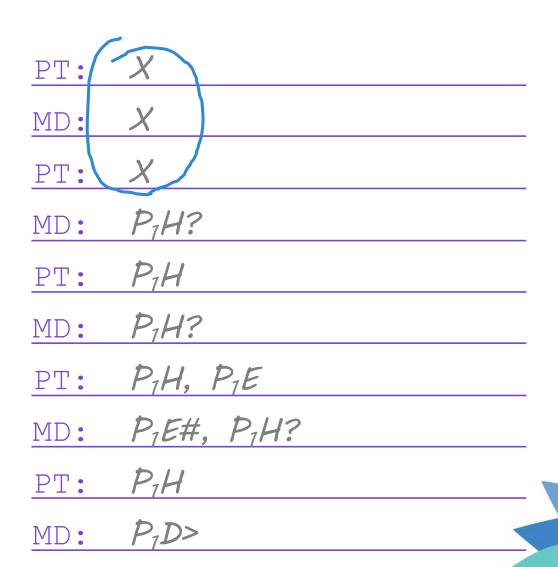
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MD:	$P_1E\#, P_1H?$
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MD:	$P_1D>$



#### Xs and Oh!

#### FROM THE OXFORD STUDY CODEBOOK

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## Sharing patient stories changes lives. And culture.



Makoul G. Using patient narrative videos for understanding better the illness experience. Academic Medicine. 1999;74:580-581. Christopher K, Makoul G. Patient Narrative Videos: Learning from the illness experience. In R Fisher & P Twohig (eds.), Making Sense of Health, Illness & Disease. New York: Rodopi, 2004.

## **Concepts of Health**

Are you healthy? How do you know?



#### **POLLING QUESTION 1**

**Physical** 

**Psychosocial** 

Are you healthy?

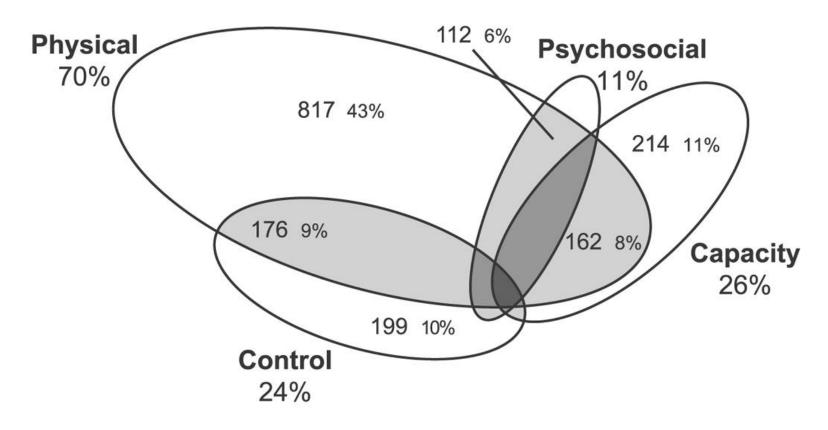
How do you know?

**Capacity** 

**Control** 



### **Concepts of Health**



Note: N=1917. Only areas with numbers shown are drawn approximately to scale. Unlabeled areas equal 34 (2%) participants or fewer.



#### **POLLING QUESTION 2**

When you hear people say why they love their doctor (nurse, et al) or they don't...

What do they say?



#### **Better communication = Better outcomes**

Patients and families feel better.



T PATIENT SATISFACTION<sup>1</sup>



**Clinical encounters** work better. PROVIDER SATISFACTION<sup>4</sup>

ADHERENCE<sup>3,5,6</sup>



## The missing link: Understanding what matters



Patient Engagement Strategies Lack Patient Voice, Consumer Input

92% of healthcare organizations value patient engagement strategies, but most do not incorporate the patient voice into designing those efforts.

1/29/2018 from Health Care Transformation Task Force



Modern medicine's true healing potential depends on a resource that is being systematically depleted: the time and capacity to truly listen to patients, hear their stories, and learn not only what's the matter with them but also what matters to them.

Dr. Rana L.A. Awdish & Leonard L. Berry, 10/09/2017



Erin Moore
@ekeeleymoore

It would be relevant to me if you joined me in what I'm doing instead of trying to "engage" me in what you're doing

#MedX

9/17/16, 11:32 AM from Stanford, CA

## Why should we care? Better care.

11%

## Visits in which clinicians have a complete picture of their patients' agenda

Christine A Barry, Colin Bradley, Nicky Britten, Fiona A Stevenson, Nick Barber. Patients' unvoiced agendas in general practice consultations: qualitative study. BMJ 2000;320:1246.

3.7x

## Improvement in health outcomes with patient contextual data

Saul Weiner, Alan Schwartz, Gunjan Sharma, Amy Binns-Calvey, Naomi Ashley, et al. Patient-centered decision making and health care outcomes: An observational study. Ann Int Med 2013;158:573.



## Opportunity: Make it easy to focus on what matters



Patients have brief encounters with healthcare providers, but deal with health more than 5,000 waking hours per year.

- Knowing what matters to them is valuable. Yet mostly unheard.
- Need an easy, systematic way to capture and share what they see as important.



Providers are busier than ever, making it harder to connect with their patients.

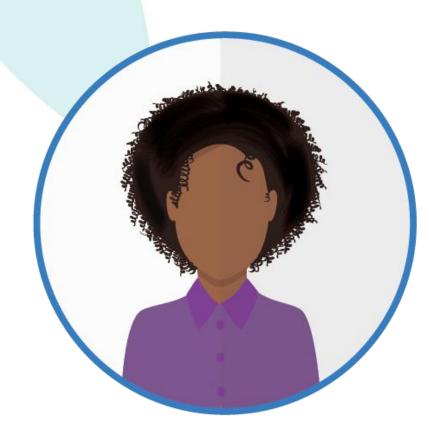
- 15 minutes per patient, 67% of time on EHR/deskwork, 54% report burnout.
- Need a quick, reliable way to learn about the whole patient in the workflow.



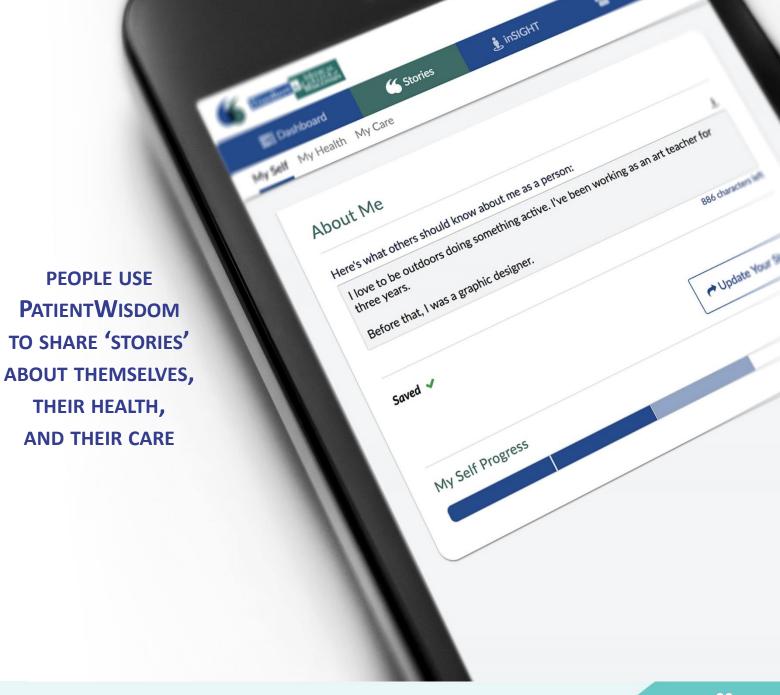
Most organizations approach patient engagement on their terms, not on patients' terms.

- True engagement improves decisions, outcomes, experience, and loyalty.
- Need clear lines of sight to meaningful summaries of patient perspectives.

## **BEFORE VISIT**



**Patients, Families, Caregivers** 



### AT VISIT



**Care Team** 







Female 31 y.o.

Jackie Sample

Call me: Jackie

**EHR** field



I love to be outdoors doing something active. I've been working as an art teacher for three years. Before that, I was a graphic designer.

#### Main Health Issue

Diabetes - Type 2



English English

> Last Updated 08/15/2017

#### This makes me happy

08/16/2017

EHR field

My family Being near the ocean

#### Health priorities / goals

Manage diabetes with diet/exercise - no meds

EHR field

EHR field

#### My agenda

Can I really handle diabetes without medicine? My leg is starting to hurt - could that be diabetes? We're thinking of having a baby - does pregnancy make diabetes worse?

#### Biggest barriers to staying healthy

Finding time to exercise It's hard to eat right when out with friends Public transportation is not convenient

#### Biggest pressure / worry

My mom is sick - I want to be there for her, but it's hard to balance everything.

#### How health affects life

I'm trying to deal with diabetes, but I've never had to think about my body in this way before. It's hard, but I'm starting to feel more confident in doing what's best for me.

Starting a painting, whether I finish it or not

Be able to do the activities I want to do - no limits

#### Challenges

Money Transport A

EHR field

EHR field

Health Ratio

I feel fine, but h

Treatment F

Health Deci

Reason

Natural

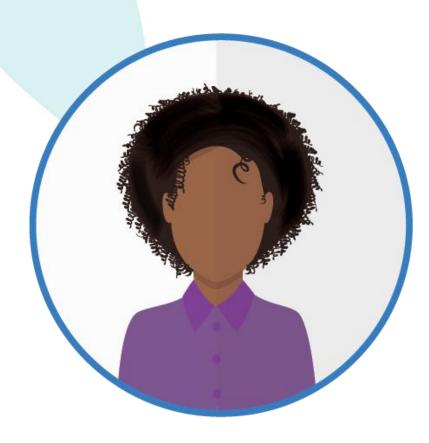
Advance Di

I do not have or

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Marc Sample [s

### **AFTER VISIT**



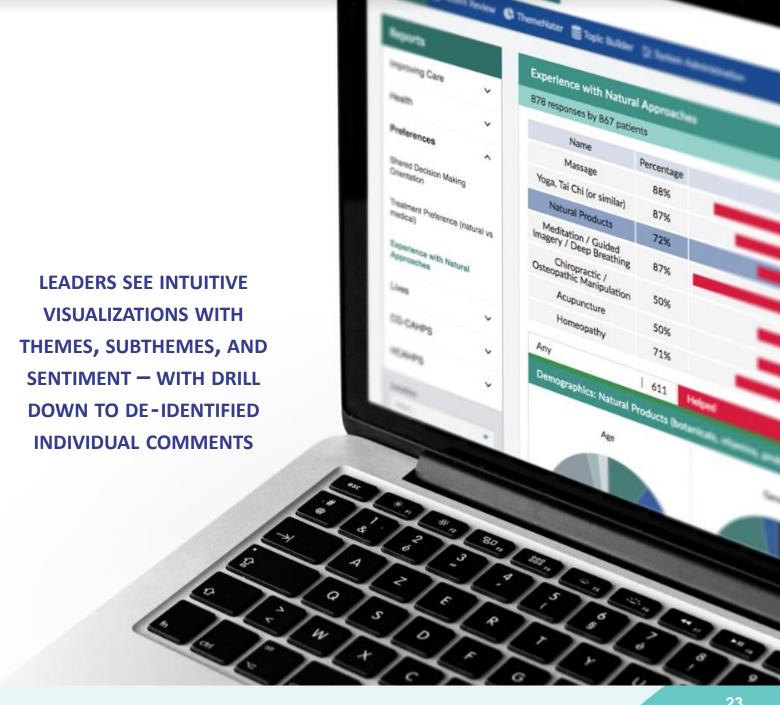
**WE CAN PING PATIENTS TO GAUGE PROVIDER COMMUNICATION** AND/OR UPDATE IDEAS **FOR IMPROVEMENT** 

**Patients, Families, Caregivers** 

## **ACROSS VISITS**



**Health Organizations** 



## Doing better without taking longer

< 20 seconds

time it takes for busy providers to read the inSIGHT summary before seeing a patient

82%

of providers confirm that PatientWisdom helps them know what's important to their patients

90%

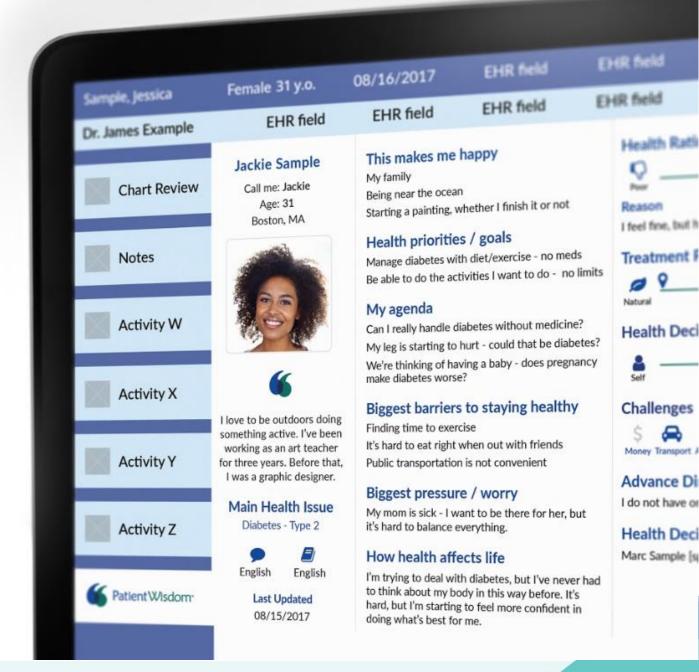
of patients say PatientWisdom improves communication with doctors who use it

95%

of visits using the inSIGHT summary rated as going 'extremely well', a marked improvement

10.7%

reduction in new patient no-show rates



## Patient perspectives: The key to real transformation

FROM
HEALTH TRANSACTIONS

Patients as cases

What's the matter with you?

Within the care setting

**Burn-out in practice** 

Disconnected

TO
HEALING RELATIONSHIPS

Patients as humans

What matters to you?

Beyond the care setting

Joy in practice

**Engaged** 

# The key to improving healthcare is to listen. Really listen.

Dr. Donald Berwick, President Emeritus, Institute for Healthcare Improvement; former administrator, CMS

We have to ask ourselves this question: What stories are we not hearing?

Sachin H. Jain, Chief Medical Information and Innovation Officer, Merck; now CEO, CareMore

# Patient engagement is the blockbuster drug of the century.

Leonard Kish, Digital Health Strategist

Dr. Farzad Mostashari, Former Head, Office of the National Coordinator for Health IT Listen to your patient; he is telling you the diagnosis.

> Sir William Osler, founder The Johns Hopkins Hospital



#### **Questions & Answers**



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Beth Lown, MD

Medical Director

The Schwartz Center for Compassionate Healthcare

Type your questions in the Questions Pane on your screen at any time.



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