

Practicing Effective Communication and Building Trust Among Patients and Researchers

8th International Conference on Patient and Family Centered Care

June 13, 2018

GHS Health Sciences Center Partners

Today's Roadmap

Session 1

Overview of Patient Engagement Studios

Communication and Trust Building

Activities to promote learning



Session 2

Patient values guiding research

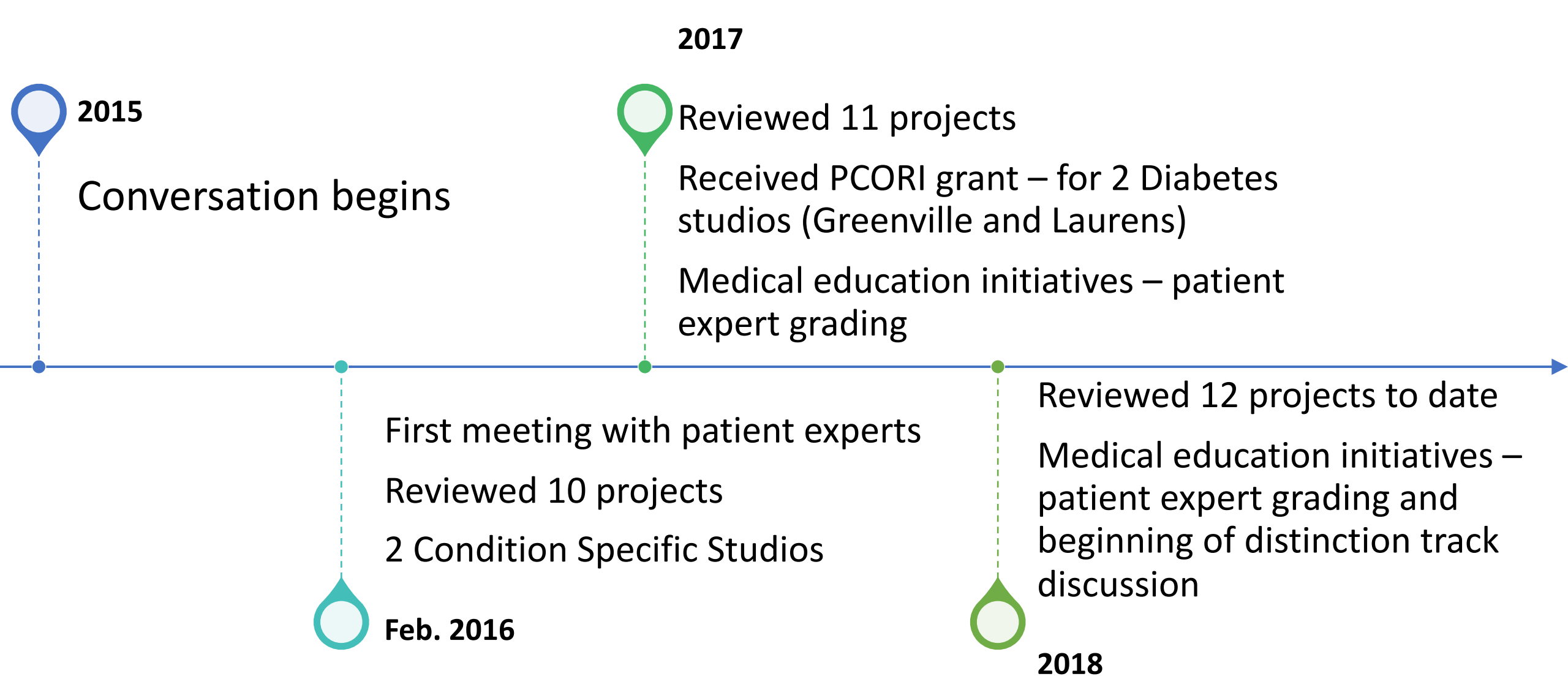
Patient creation of a shared decision making tool

Presenters

- Cole Brown – Patient Expert
- Pam Evans – Patient Expert
- Johnny Payne – Patient Expert
- Jessica Sterling – Patient Expert
- Ann Blair Kennedy – Studio Co-Director
- Peggy Wagner – Studio Director



GHS Health Sciences Center Partners



Timeline of Patient Engagement Studio

Patient Engagement Studio Steering Committee

8 Patient Experts

3 Clinicians

2 additional
researchers

Studio Director and
Co-Director
(researchers)

Support staff

Condition/Population Specific Studios

Breast Cancer
Studio

Rheumatoid
Arthritis Studio

2 Diabetes Studios
(Greenville and
Laurens County)

Future Condition /
Population Specific
Studios

- Adolescent/Young Adult
- Autism

Understanding is a two-way street.

– Eleanor Roosevelt





Primary Negotiation: Sustaining Basic Trust

**Social Negotiation:
Maintaining Mutual
Respect**





**Issue Negotiation:
Getting Down to Brass Tacks
Bring patient experience to research**

In Other Words . . .

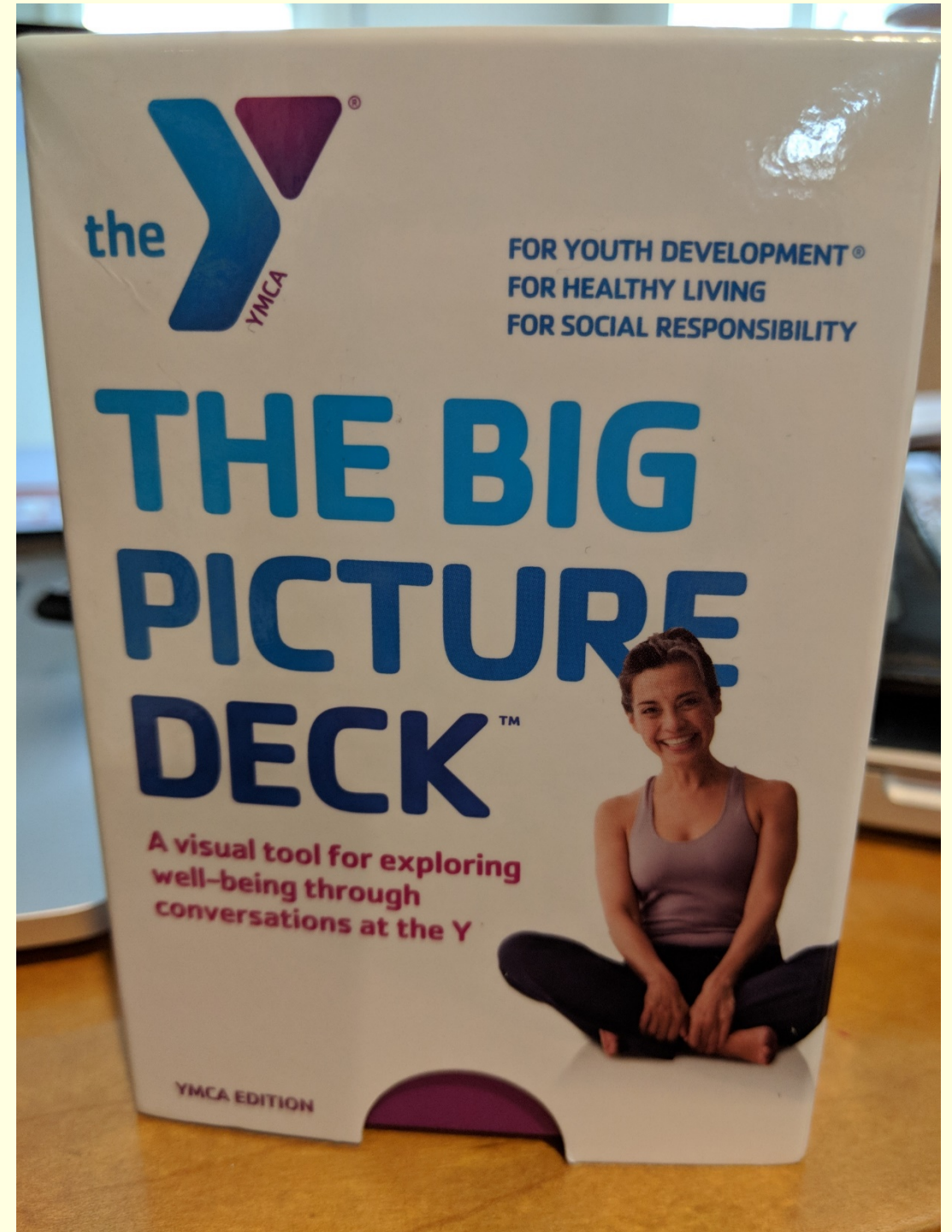
Do we trust each other?

Do we respect each other?

Can we work together?

Example 1. . .

- How did that make you feel?
- What did you learn?
- Do you think you could use this with your patients?



Example 2. . .

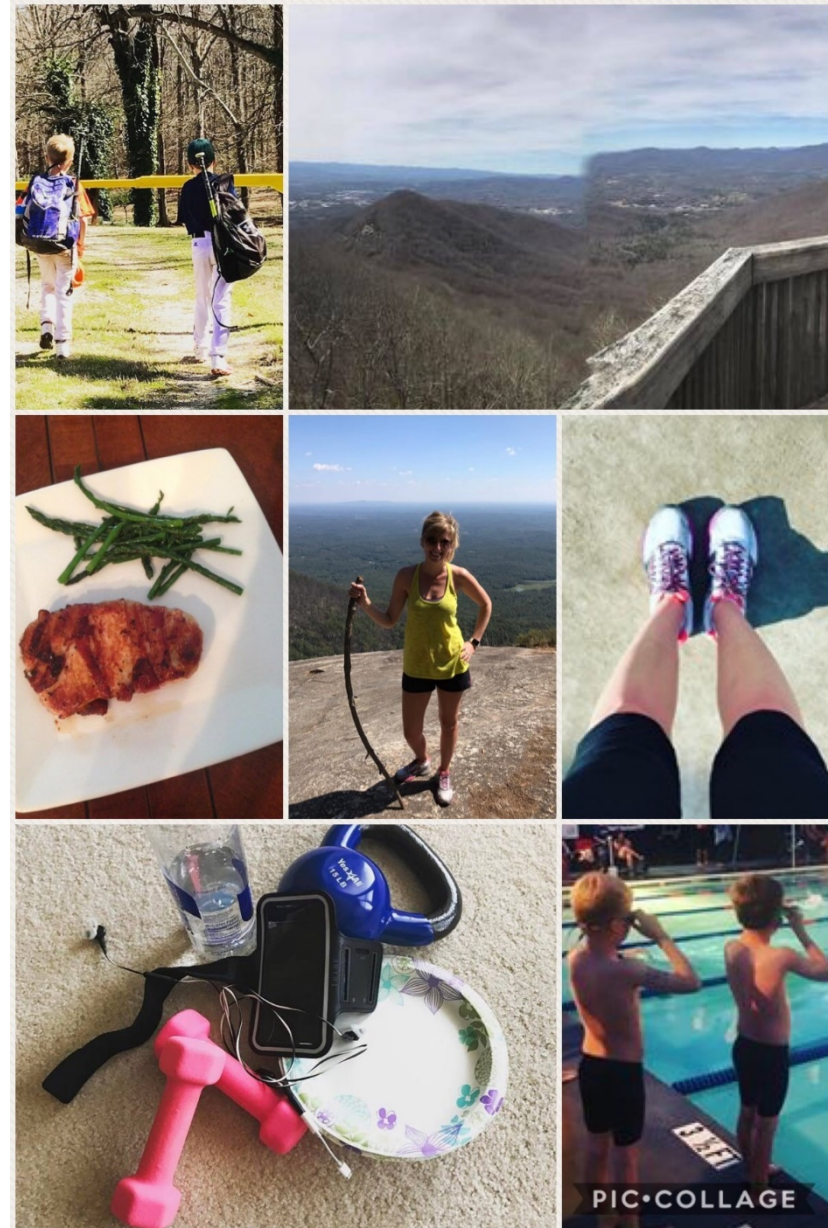
PhotoVoice Project 2018:
Steering Committee

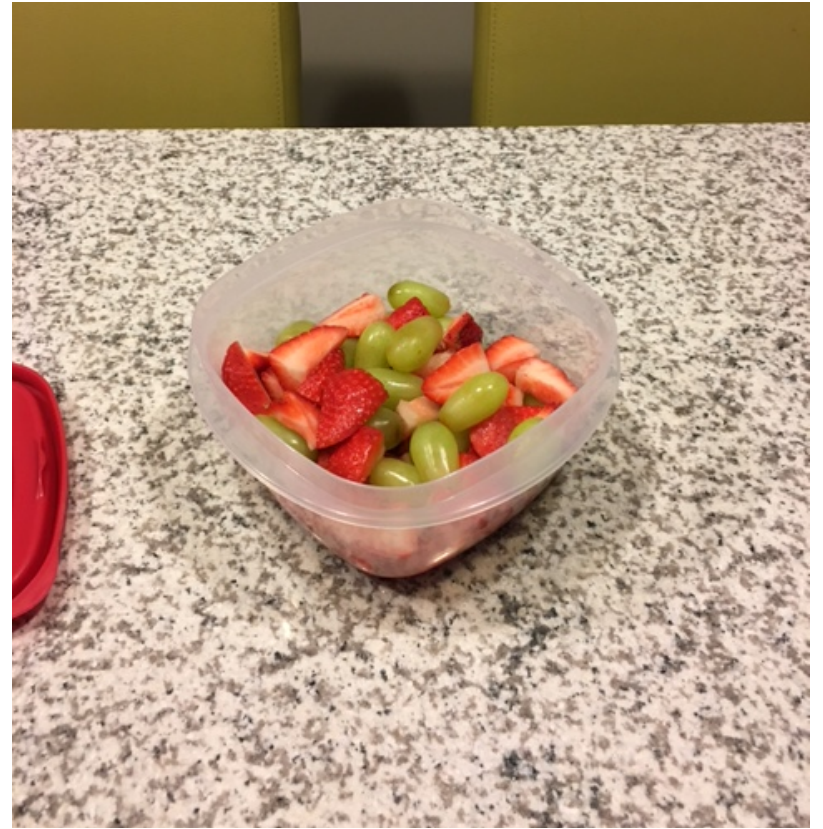




Johnny P.

Jessica S.





Cole B.



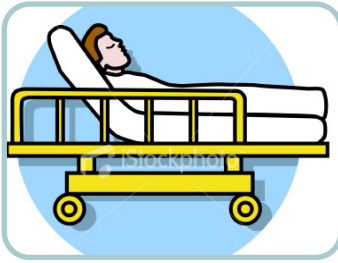
Pam E.

Example 3 . . .

Translating Patient Questions to Research Questions

PATIENT QUESTION	RESEARCHER QUESTION
Why do I have diabetes?	What is the etiology of diabetes?
What can the health system do to help me?	Can we compare two or more interventions to see which works better?
How can I partner with a doc rather than follow them blindly?	Is there a more effective way for patients to engage in the health care discussion with their provider?

Components of a Well-Built Research Question



P

- Patient/Population: detailed



I

- Intervention (or exposure): therapy, diagnostic test, “the variable”



C

- Comparison Intervention: “the control”



O

- Outcome(s): difference in performance of the interventions, “the results”

POPULATION -

REDUCE RISK OF DIABETES

I = INTERVENTION -

TYPE II
NEWLY DIAGNOSED, DIABETICS - W/O DIABETES MEDS (W/A1C > 7.5)

ASIAN FOOD = 2 SERVINGS PER DAY

C = CONTROL / COMPARISON -

NEWLY
DIAGNOSED NOT EATING ASIAN FOOD
TYPE II

O = OUTCOME - REDUCED A1C

THE PURPOSE OF OF STUDY IS TO COMPARE THE EFFECTIVENESS OF
ASIAN FOOD VS. STANDARD AMER DIET ON H1C REDUCTION AMONG NEWLY DIAGNOSED TYPE II

Financial (and
emotional)
Support

Greenville Health System
Health Sciences Center

University of South Carolina
School of Medicine Greenville

Patient Centered Outcomes
Research Institute (PCORI)

Engagement
Champions
Windsor Sherrill
and Matt Hudson

Priscilla Kendrick
and Karen
Edwards

Patient Expert
Steering Committee
Members (not in
attendance)

- Jaime Fivecoat
- Mary McCarthy
- Chris Przirembel
- Ron Critzer

Patient experts from
the Breast Cancer
Panel

Patient experts from
the Laurens and
Greenville Diabetes
Panels

Patient experts for
special topics

Research, clinical,
and patient
experience partners

Acknowledgements