CHOICE
Coalition of Hospices Organized to Investigate Comparative Effectiveness

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Outline

❖ The CHOICE research network

  » History as a research network

  » Now: Benchmarking

❖ Benchmarking: preliminary results of the first round

❖ Next steps: building a "learning healthcare system"

❖ Lessons learned

JR:

- JR is a 54 year old man who is admitted to home hospice with metastatic colon cancer.

- He has moderate pain (5/10) on admission, for which he is taking OTC acetaminophen.

- His wife is overwhelmed with caregiving and is particularly interested in learning about resources for caregiving support.

- At the initial visit, JR appears withdrawn and lets his wife do most of the talking.

Questions

- Questions raised at the first IDT meeting include:

    - Which opioid offers the best side effect profile?

    - Should JR be screened for depression?

    - Would a family conference and discussion of his treatment goals lead to better outcomes?

    - What is the optimal visit frequency in the first week? In the second week?

The CHOICE network

- Started in 2012
- 3 hospices:
  - Agrace
  - Hospice and Community Care
  - Empath
- Agencies agreed to share data and help ensure data validity and reliability
- Initial focus on <u>research</u>

The CHOICE mission:

❖ To define pathways for safe, effective, and efficient hospice care

CHOICE

Coalition of Hospices
Organized to Investigate
Comparative Effectiveness

www.choicehospices.org

Staying on mission is challenging…

CHOICE

- ❖ Academic-community-business partnership
- ❖ Leverages existing hospice EHR data
- ❖ <u>Lean and sustainable</u> business model based on data infrastructure:
  - » Value proposition is based on operations-based return on investment: Benchmarking
    - Operations
    - Quality
  - » Research is an added benefit

How CHOICE works:

University of Pennsylvania analyzes merged data, identified by linking code*

Data analysis (Data with indirect identifiers—codes)

Solutions merges data and replaces unique identifier with a code.

EHR data for merge

CHOICE hospices contribute EHR data with unique EHR identifier

Clinical data

Outcomes/survival

Visits

HIS items

*Codes remain on hospice server

CHOICE ground rules

❖ Only one person (DC) sees all hospice results

❖ No sharing of data

  » To CHOICE members

  » To outside researchers

  » To national organizations (NHPCO/NAHHC)

  » To CMS

CHOICE hospices (Phase I)

- Hospice of the Bluegrass
- Empath
- Mesilla Valley
- Community Hospice of Texas
- Agrace Hospice
- Western Reserve

- Arbor Hospice
- Faith Presbyterian Hospice
- Hosparus
- Hospice and Community Care
- Hospice by the Bay
- Hospice of Austin

CHOICE Phase I dataset

❖ N=164,314

❖ 5 years of data from 14 hospices

❖ Geography: Midwest, Northeast, West, Southeast US

❖ Size: ADC range 200-2,000

❖ LOS:

> » Median: 23 days
> » 26% referred in last week
> » 9% in last day

Patterns of Functional Decline in Hospice: What Can Individuals and Their Families Expect?

Pamela Harris, MD,* Esther Wong, BA,† Sue Farrington, MBA,‡ Teresa R. Craig, CPA,‡ Joan K. Harrold, MD,§ Betty Oldanie, RN, BSN, MA,¶ Joan M. Teno, MD, MS,** and David J. Casarett, MD, MA†

The "Comfortable Dying" Measure: How Patient Characteristics Affect Hospice Pain Management Quality Scores

Lauren Kelly, MS,[1] Laura Bender, BA,[1] Pamela Harris, MD,[2] and David Casarett, MD, MA[3]

Which Hospice Patients With Cancer Are Able to Die in the Setting of Their Choice? Results of a Retrospective Cohort Study

Neha Jeurkar, Sue Farrington, Teresa R. Craig, Julie Slattery, Joan K. Harrold, Betty Oldanie, Joan M. Teno, and David J. Casarett

Can Hospices Predict Which Patients Will Die Within Six Months?

Pamela S. Harris, MD, FAAPMR,[1] Tapati Stalam, BA,[2] Kevin A. Ache, DO,[3] Joan E. Harrold, MD, MPH,[4] Teresa Craig, CPA,[5] Joan Teno, MD, MS,[6] Eugenia Smither, RN, BS, CHC, CHE, CHP,[7] Meredith Dougherty, MS[8] and David Casarett, MD, MA[8]

SUNCOAST SOLUTIONS
THE POWER TO CARE

Idea development

❖ Idea from CHOICE member→ creation of a 'pilot' abstract.

❖ Steering committee reviews for concerns related to feasibility, implications, and privacy.

❖ Steering committee also suggests a working group to develop the paper.

❖ A working group is formed (3-6 members).

❖ Final paper is circulated to the steering committee.

One example: Can frontline clinicians predict patients who are likely to die very soon?

Nurses' predictions: The art of prognostication

- ❖ "Is death imminent?" question analyzed for one hospice (n=9,034)
- ❖ Best accuracy (ROC area) was for 1-week prediction
- ❖ Nurses accuracy: 83%
  - » But: sensitivity is only 53%
- ❖ Could a statistical model do better?

Developing a prognostic index

❖ Logistic regression model (7-day mortality)

❖ <u>Developed in one hospice, tested in 2</u>

❖ Prognostic weights for variables defined by model β coefficients

❖ Scaled from 0-5 and rounded to nearest whole number:

» 0: worst prognosis

» 5: best prognosis

Best model (Bayes Information Criterion):

❖ PPS score

❖ Admitted from hospital vs. other location
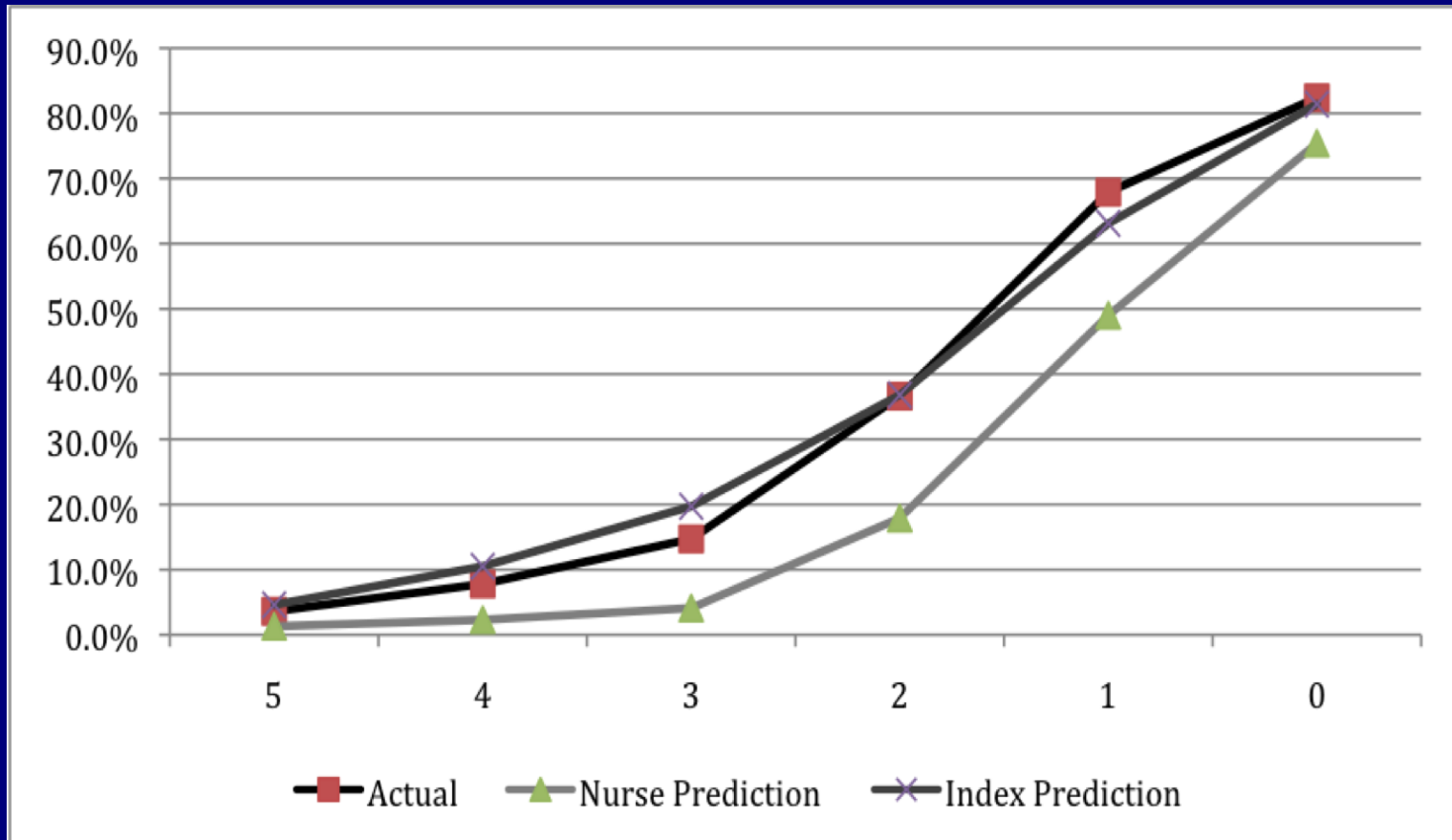
❖ Gender

Art vs. Science

❖ Clinicians
  » Sensitivity: 53%
  » Overall accuracy: 83%

❖ <u>Model</u>
  » Sensitivity: 85%
  » Overall accuracy: 89%

Actual vs. predicted mortality

Broader testing:

❖ Tested in an additional 10 hospices

❖ Accuracy range: 0.78-0.91

❖ Factors influencing accuracy:

» Diagnostic mix

- Model accuracy varies among diagnoses
- Lowest for stroke; highest for cancer
- Hospices serve different patient populations

» Staff training

- PPS is staff dependent
- Hospices offer varying training and oversight

Strengths of an academic/community/industry partnership

❖ All "next step" research questions could be answered:

» Without additional funding

» In parallel (3-5 studies ongoing at the same time)

» Very quickly

❖ 3-4 months from idea to paper:

» Steering committee identifies high-priority questions

» Hospices agree to participate in a project
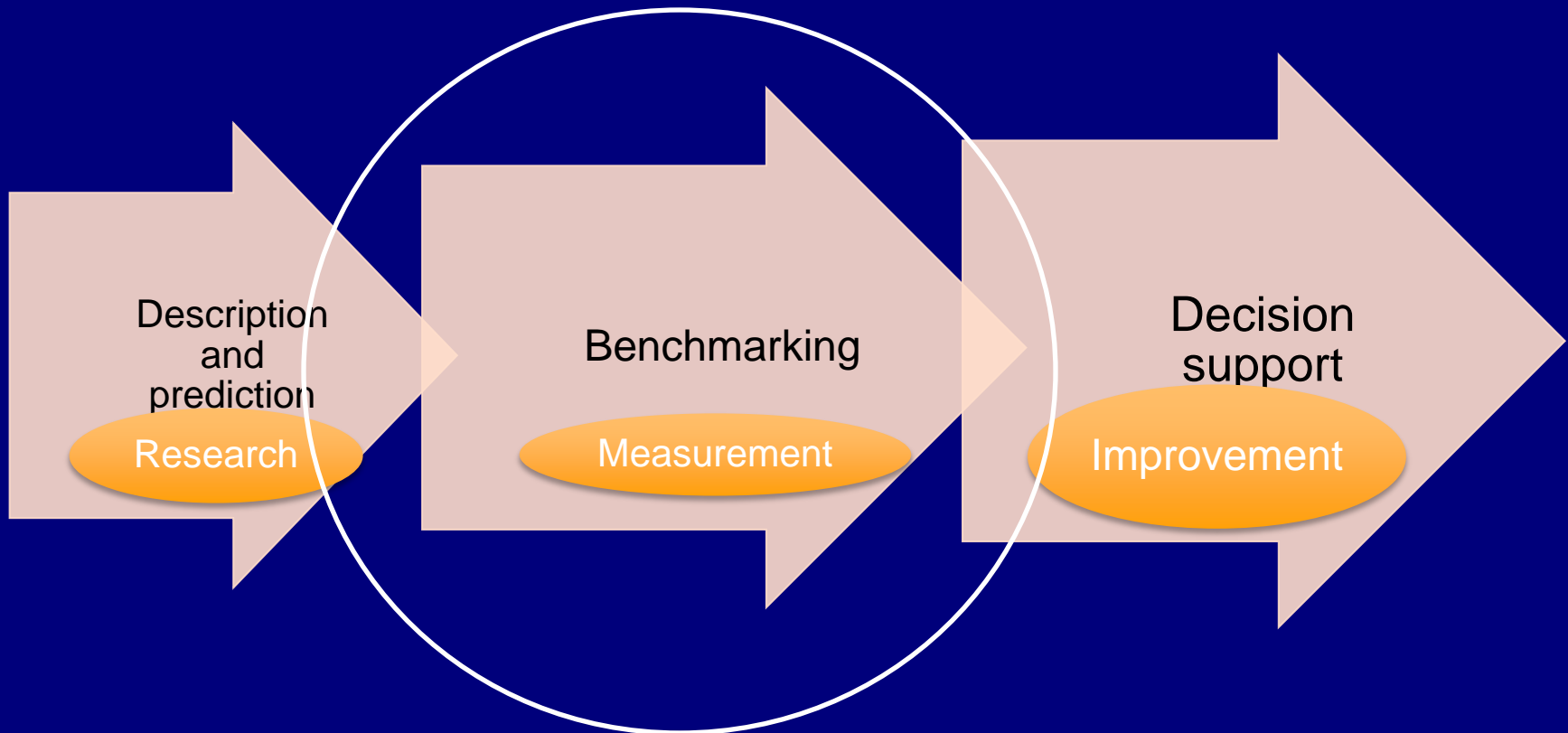
» Analysis (4-8 weeks)

» Manuscript review and submission

What's next?

❖ Proven ability to extract data reliably from multiple hospices

❖ Familiarity with key data elements

❖ Sophisticated analytics

❖ Working partnership between hospices/Solutions/Penn

CHOICE→What's next?

Description and prediction — Research

Benchmarking — Measurement

Decision support — Improvement

Goal: <u>Maintain</u> research, <u>add</u> benchmarking

The benchmarking challenge

❖ Increasing regulatory scrutiny and impending public reports mean that we need to understand…

…how well we're doing, and

…how we can improve…

…<u>before someone else tells us</u>.

Preliminary benchmarking results

❖ Hospices:

  » 41 hospices with complete HIS items

  » 27 hospices with complete visit data

❖ 306,329 patients total

❖ 18,382 with HIS data
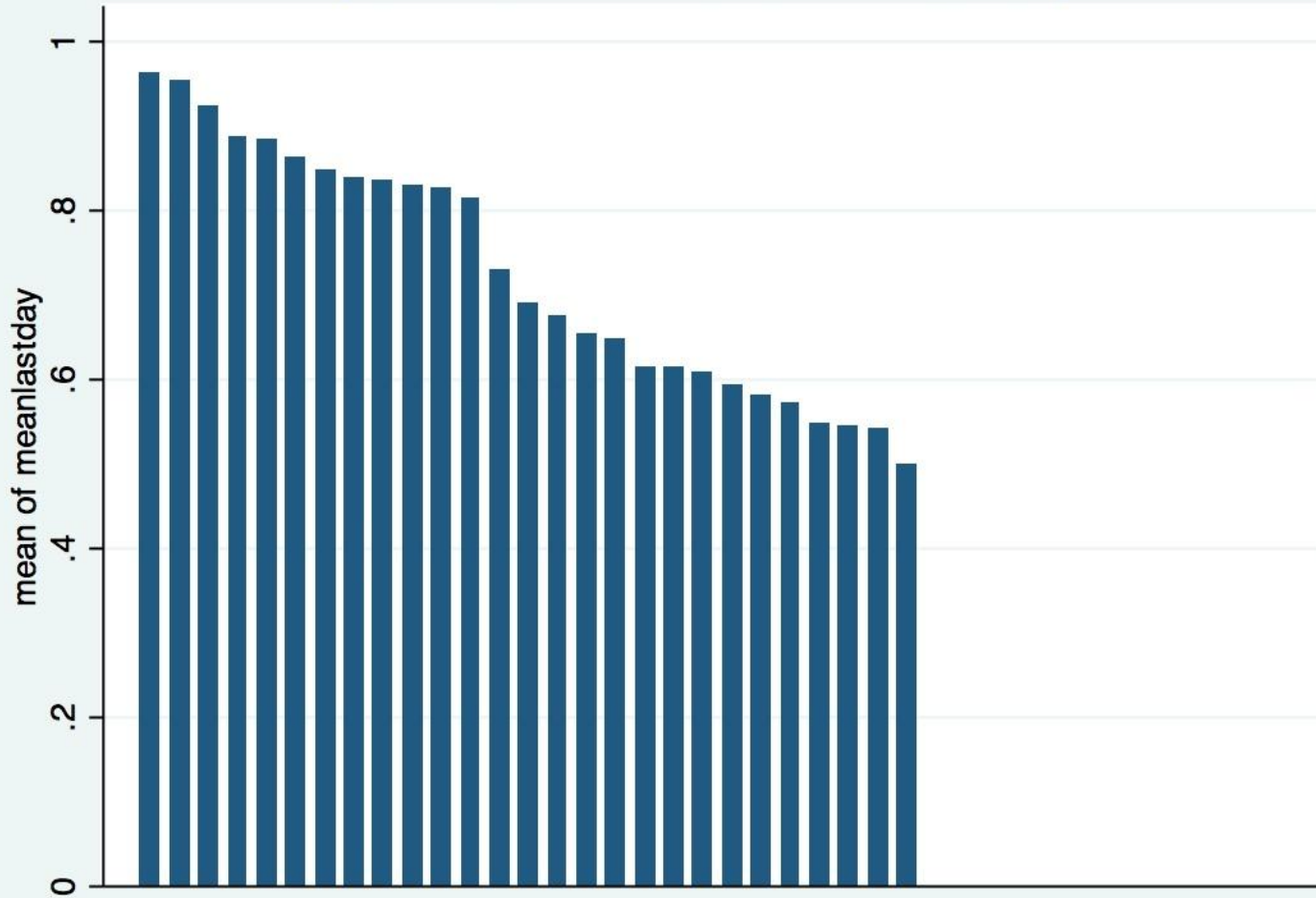
What are we benchmarking (now)?

❖ Operations:
  » Visit on last day of life
  » Weekend admissions

❖ Quality (all HIS items)
  » Bowel regimen
  » Asked about spiritual concerns
  » Pain assessment
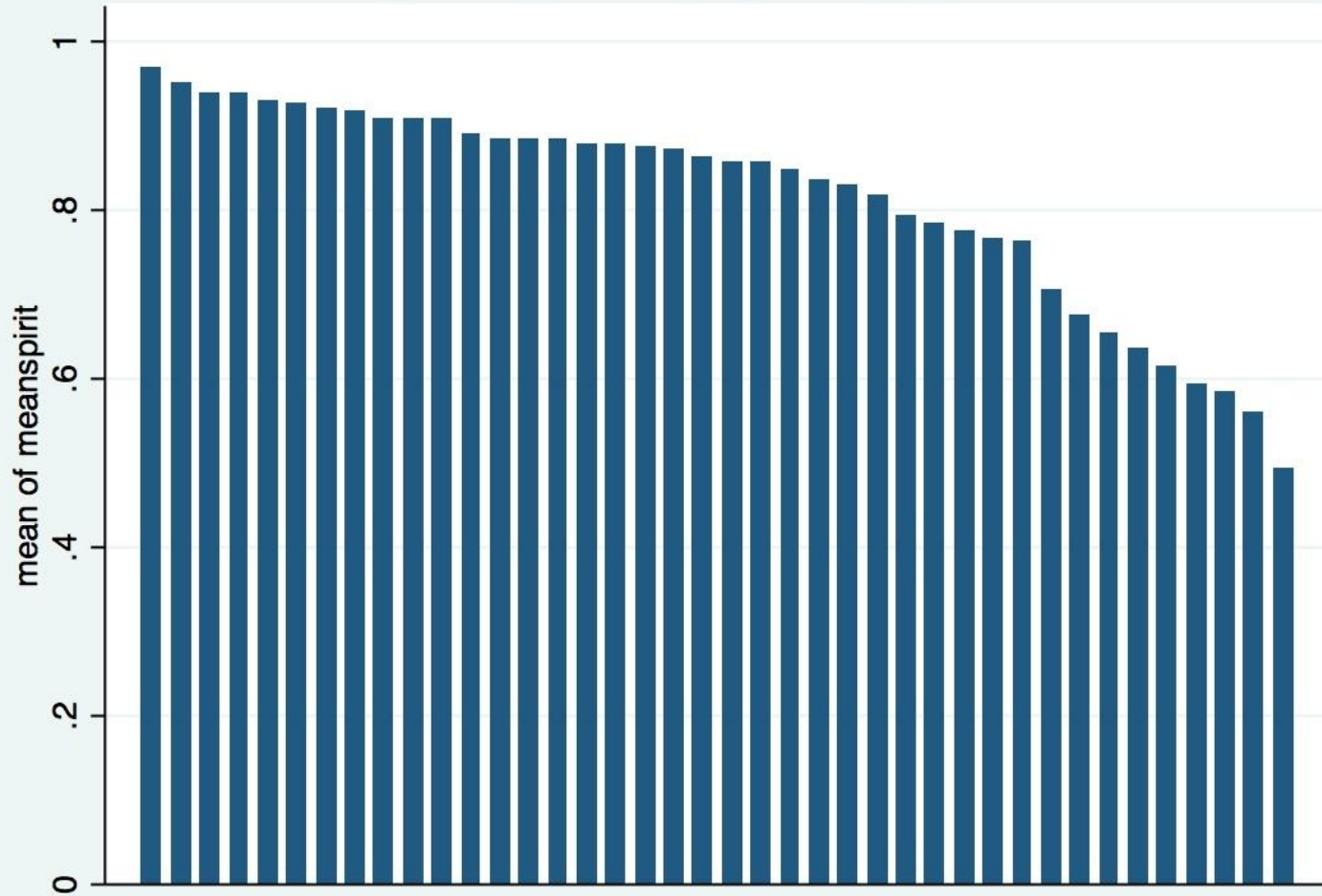 » Pain assessment tool used
  » Dyspnea screen
  » Dyspnea treatment

% of patients with a visit on the last day of life

*Only routine patients on last day

Spiritual assessment

❖ (Relatively) wide variation

❖ Variation:

  » Lower for weekend admissions (73% vs. 78%)

  » Lowest for inpatient (83%); highest for home (89%)

❖ Success stories: One high-performing hospice asked its spiritual care providers to train nurses to start the conversation.

Summary…so far

❖ Wide variation in weekends and visits

❖ Less variation in HIS items

    » Some do vary

    » Others not very useful (e.g. pain assessment)

❖ <u>Beware items with a ceiling effect</u>

❖ Predictors (so far):

    » Hospice

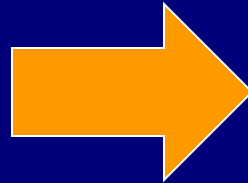   » Initial site of care
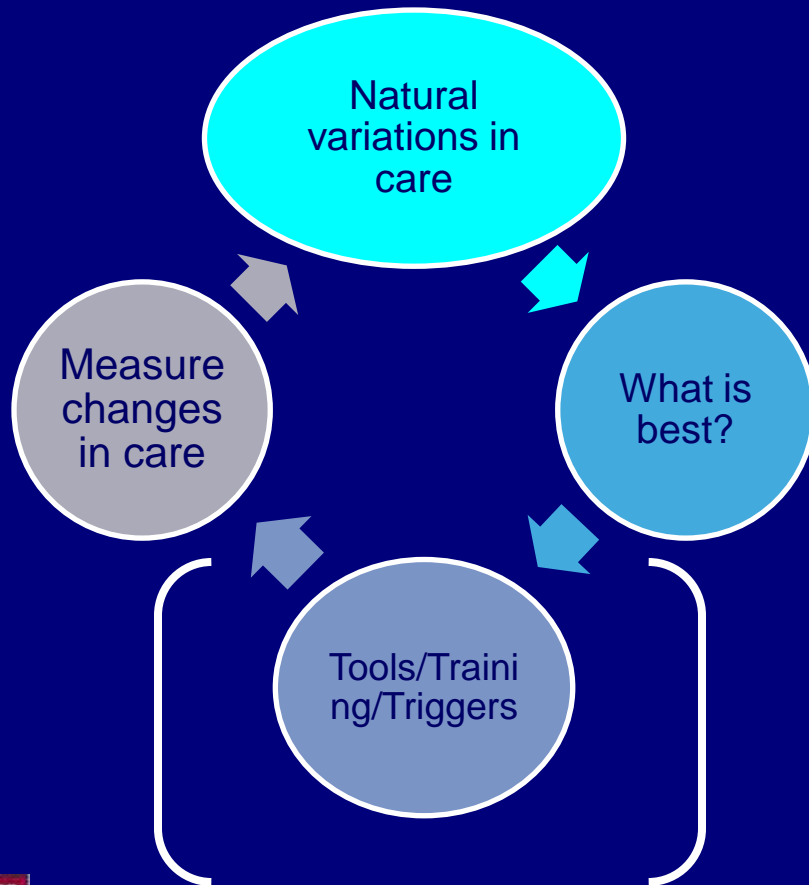
    » Diagnosis

    » Short LOS

What hospices will see

❖ Reports in EMR

❖ User-run (any time)

❖ Reports include:
  » My hospice's data
  » Community means, medians, and percentiles
  » Divided by patient subgroups

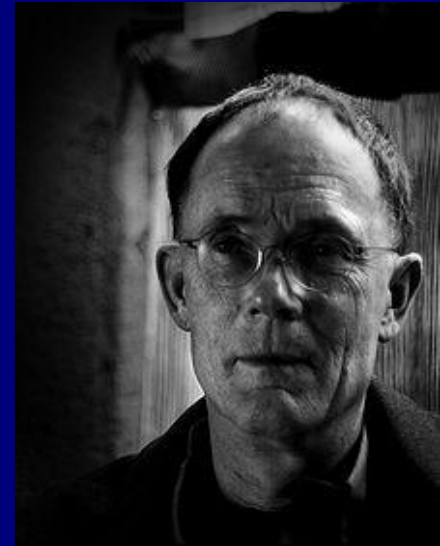# Analysis = Data → Information

CHOICE: A "learning healthcare system"

- ❖ "Background" data collection
- ❖ Patient-level data
- ❖ Sophisticated analysis
- ❖ Speed/rapid turnaround

The real value of benchmarking

❖ "The future is here now. It's just not very evenly distributed."

-William Gibson

Reflections and lessons learned

❖ Academic-commercial partnerships can be valuable

❖ Goals aren't always aligned

❖ Lack of control over operations

❖ Uncertainty and vulnerability

Academic-commercial partnerships can be valuable

❖ In theory, a very efficient way to collect data

❖ Allows creation of an infrastructure that would normally cost much, much more

❖ Ready-made population of hospices

❖ Pre-built system of communication (e.g. steering committees, newsletters)

Goals aren't always aligned

❖ Commercial entities need to turn a profit and need to keep clients and shareholders satisfied

❖ Can create pressure on academic partners to demonstrate value

Lack of control over operations

❖ Very different than 'pure' research in which you hire, train, and oversee staff

❖ Need to rely on a company for operations and data

❖ No direct control over timing, schedules, and data quality

Uncertainty and vulnerability

❖ Companies change
❖ They go out of business, they get purchased, and they get new leadership

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❖ **Lessons learned**