

Information Knowledge and Development: A Perspective on Patient-Centric Feed Forward “Collaboratories”

**Engineering a Learning Healthcare System:
A Look at the Future
Institute of Medicine
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Aim of Presentation

- **“to highlight complexities in and impediments associated with generating clinical information and knowledge, as well as to reflect on systems changes or incentives that might address the various asymmetries and barriers to using clinical data for health learning.”**
- **Take all the time you need**
- **You will have 15 minutes**

Topics

1. **The Problem**: Disconnected, partial data on patients' health and healthcare overtime
2. **The Fundamental Idea**: Feed Forward & Feed Back Information System Embedded in Front-line Clinical Microsystems
3. **A Case Study**: Dartmouth Spine Center, National Spine Network and NIH Research
4. **Convolutions and Solutions**: Feed Forward and Feedback “Collaboratories” ... A Model and Some Complexities, Impediments and Path Forward

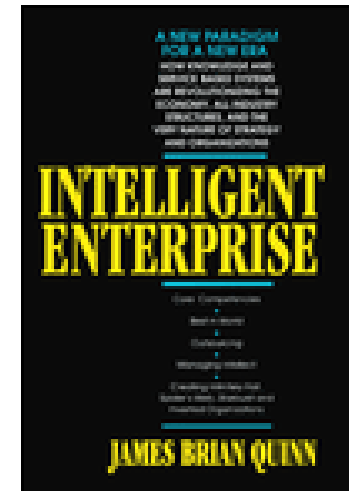
Note: Thanks to colleagues: James Weinstein, Elliott Fisher, Paul Batalden

1. The Problem

- **Disconnected, partial data on patients' health, healthcare, outcomes & costs over time**
 - **Bad for patient care**
 - **Bad for program improvement**
 - **Bad for clinical research & health professional education**

Brian Quinn: Pre-Spine Center

- Brian Quinn ... 62 year old Business School professor with history of **disabling low back pain**
- 6 prior flare ups in past decade ...**unable to function** for days to weeks
- **Episodic treatments** by different clinicians in different practices
- Brian Quinn had concluded ... “**nothing works** to prevent the problem, no one knows what causes these flare ups, and treatments have not worked except some reduced the pain in the short term”
- The doctors and practitioners do not talk to each other, do not look at my past treatments and **do not know what treatments I have gotten & the results**
- Every time I have a back problem, we start all over **from scratch** ... history, physical, x-rays, cat scans, with no one learning anything from my earlier treatments & **no good research to know what treatment is likely to work best for a person like me**
- I would guess that I have cost Blue Cross about **\$55,000 on medical care** -- ED, visits, meds, surgery & my time lost from work might run about 120 days in past 10 years ... conservatively over **\$120,000 in lost productivity**



Based on actual case

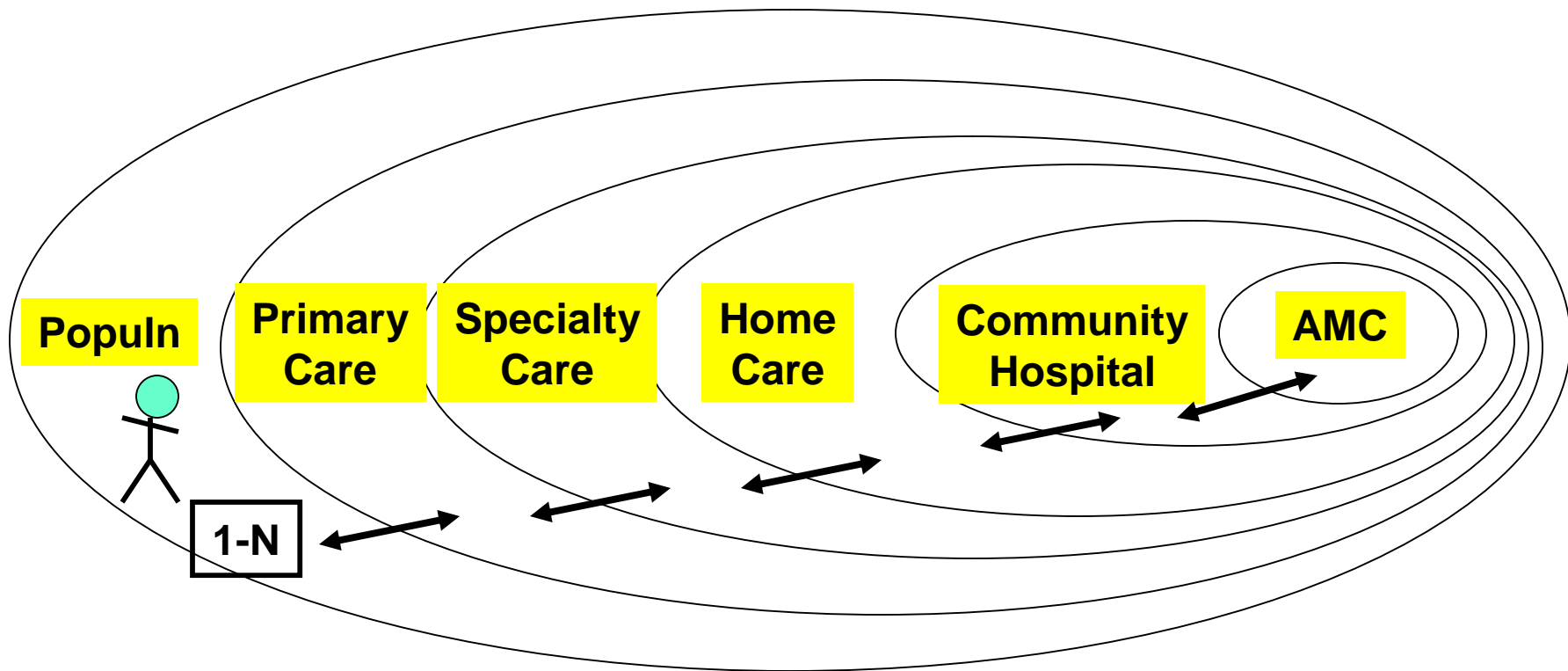
The Problem & Some Sources

1. Inadequate information for patient care
 - Data does not “follow” the patient
2. Inadequate information to understand and improve process of care
 - Data not turned into information to guide treatment
 - Data not turned into information to learn from every patient for research
3. Limited quality measures to support public reporting
 - Data systems inside organizations are not integrated nor interoperable across organizations
4. Inadequate information for research
 - Data often not standardized & data health outcomes/costs are partial

Feed forward data systems to learn about every patient & to learn from every patient à care + research

Feed Forward Data Challenge:

To keep the data with the patient/population as they travel through the system & to link patient level data with microsystem & macrosystem and community level data



Source: Nelson EC, Batalden PB, Mohr JJ, Plume SK: Building a Quality Future. *Frontiers of Health Services Management*, 15(1):3-32, Fall 1998.

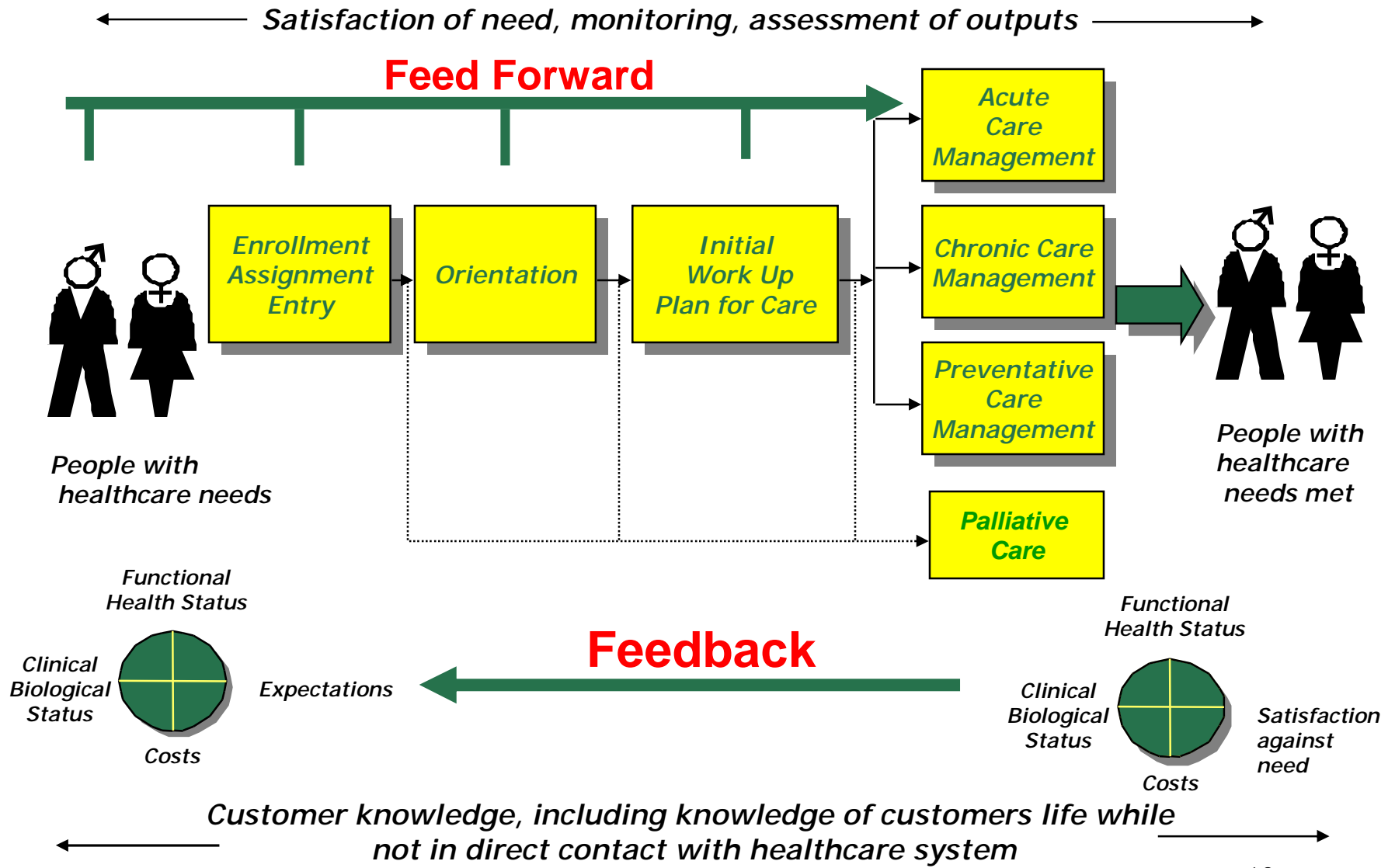
2. The Fundamental Idea

**Feed Forward & Feed Back
Information Systems
Embedded in Front-line
Clinical Microsystems**

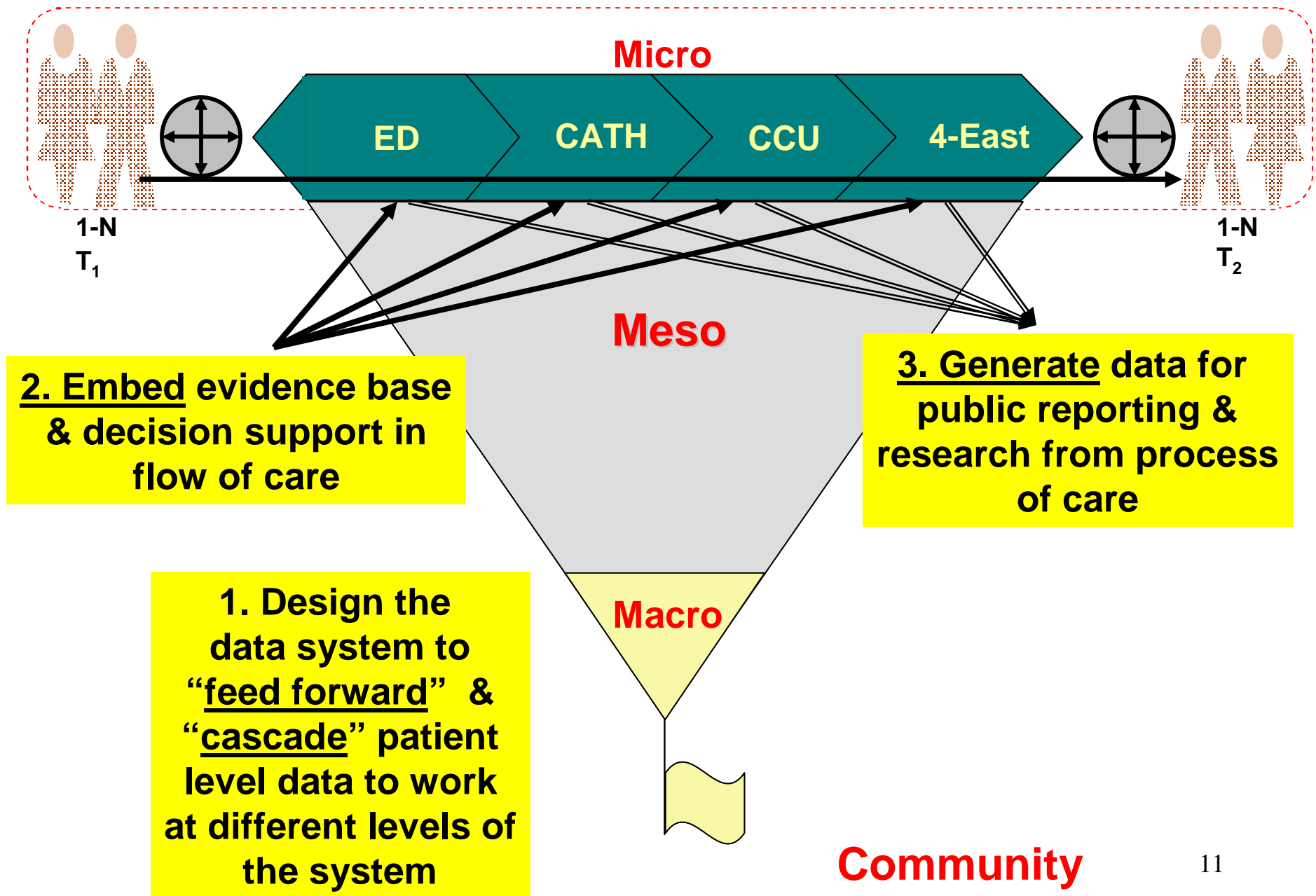
Feed Forward & Feed Back Info Systems

- **Feed Forward**: Gathers patient data as care is delivered the first time possible & moves the data/displays forward as the patient's health care experiences progress so that patient and providers can know what they need to know and do the right thing at the right place at the right time
- **Feed Back**: Gathers data at the level of the individual patient, a subpopulation of patients, or an entire population of patients and displays the data for prospective management of the patient, for evaluating, managing & improving patient care and processes, & to serve as a database for research (basic, translational, outcomes) and health professional education

A General Clinical Microsystem



Data Challenges: Embed, Feed Forward, Generate & Cascade



For useful electronic health records it is not enough to have ...

1. It is not enough to have

- Standardized nomenclature for the essentials: tests, treatments, diagnoses, allergies, medications, etc.
- Interoperable data systems to bring together different data streams from different organizations,

2. But also, need

- Patient-centric, feed forward information systems ... to manage/improve patients and processes and to serve as research data base for better health outcomes for better quality and for better value. Patient-centric calls for:
 - **measurement** of health status and health outcomes that's consistent with IOM definition of health
 - ability to **follow** patients over time as they move in and out of different parts of the healthcare system and to enable aggregation of data at different levels of the health system (micro, meso, macro, community)
 - use of **patient-report** as well as **clinician-report** of health status and health-related data

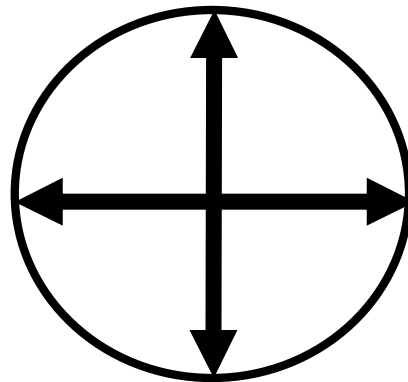
IOM Definition of Health

- **Health is a state of well-being and the capability to **function** in the face of changing circumstances. (IOM)**
 - **“Health is a positive concept emphasizing social and personal resources as well as physical capabilities. Improving health is a shared responsibility of health care providers, public health officials and a variety of actors in the community who can contribute to the well being of individuals and populations” - IOM**

To Measure Health Status & Outcomes ... Need both Clinician and Patient Reported Data

- Physical
- Mental
- Social/Role
- Perceived Well-being

Functional



Clinical

- Morbidity
- Mortality

Satisfaction

- Health Care Delivery
- Perceived Health Benefit

Costs

- Direct Medical
- Indirect Social

3. A Case Study

**The Dartmouth Hitchcock Spine Center,
National Spine Network & NIH Research**

Dartmouth Spine Center

Example of Feed Forward & Feed Back Data System

Other Feed Forward Leaders: Geisinger (autism), Karolinska (rheumatoid arthritis), Dartmouth (breast cancer, carpal tunnel, vascular, etc.)

Dartmouth Spine Center

- **Feed forward value compass data**
 - **Patient-based data entry for “today’s”**
 - Symptoms & functional status, patient perceptions, costs
 - **Clinician fixed-field data entry for “today’s”**
 - Diagnoses, tests, treatments, morbidity
 - **Database used locally for patient care and improvement**
 - Shared decision-making
 - Outcomes tracking
 - Program evaluation & improvement
 - **Database used nationally for research**
 - National Spine Network
 - Conduct clinical research

**Key Principle: Design data streams to support:
front line work processes + program improvement + clinical research**

Spine Center Process

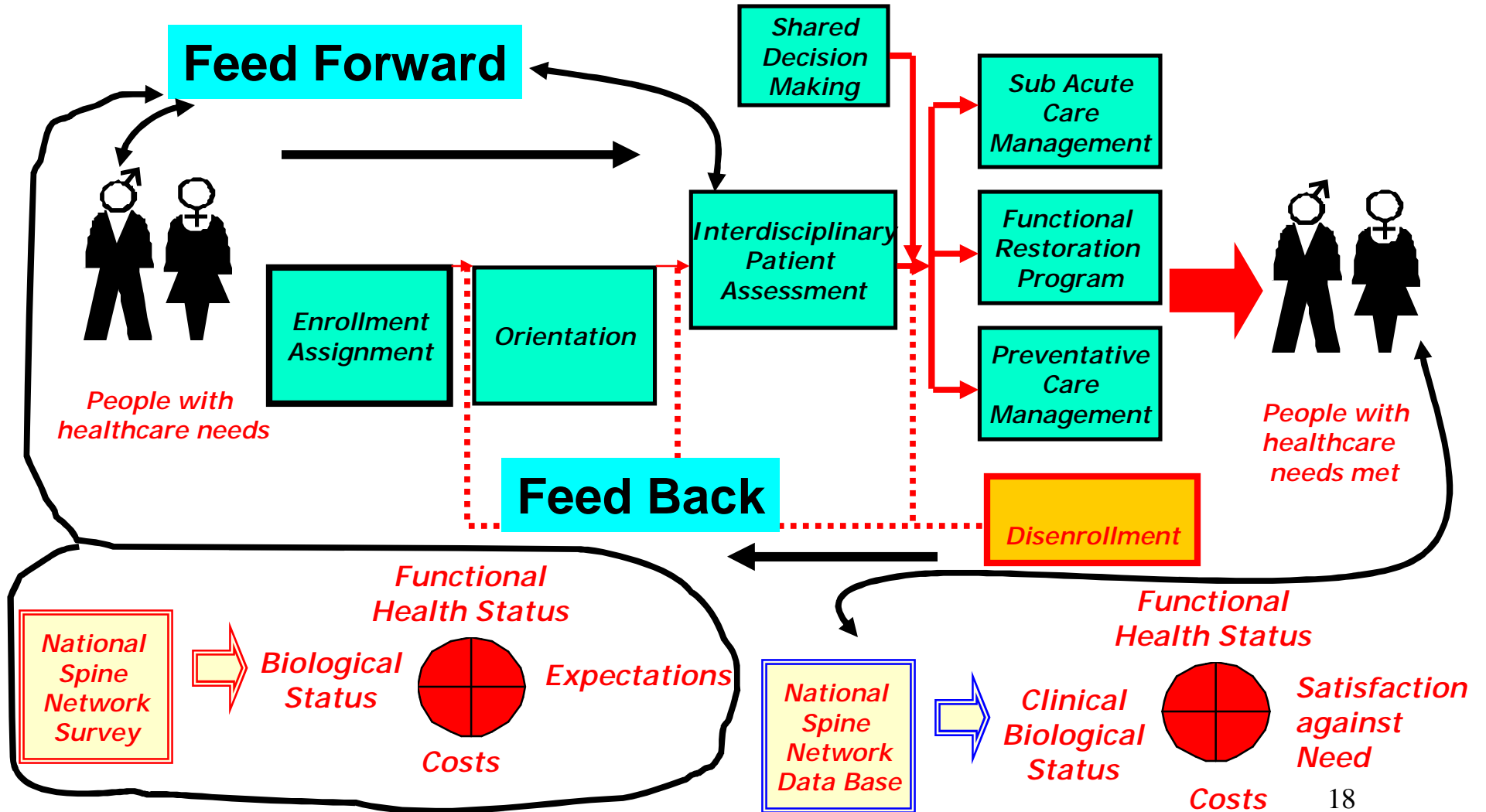


Figure 9.1 Feed Forward and Feed Back Data for Use in Patient Care, Program Improvement and Clinical Research

Touch Pad Technology

**Patient May
Complete the
Survey
Standing up...**

**... Or Seated
in the Waiting
Area.**



....then returns it to the Receptionist

Print Patient Summary Report



***Deliver
Patient
Summary
Report to
Exam-room
Door.***



***Share
Summary
Information
With Patient***



Patient Summary Report – Dartmouth Spine Center

Functional Status

Appointment: Spine Clinic; RHV; 09/19/2006
Survey Group: Spine Followup; completed on 09/19/2006; 19 mins
Reason for visit:

Personal Summary (as of 09/19/2006)
Demographics: Female; 80 yrs old; Married; Some college or technical school
Working Status:
Social: Lives alone
Work Disability (as of 09/19/2006)
Legal action: None - I am not considering any legal action
Health History (as of 09/19/2006)
Current conditions:
Condition history: High blood pressure; Uterine cancer; Other chronic pain
Previous Surgeries: Uterine cancer; Not sure - pain
Hospitalizations, Cancer: 1
Family history: Asthma; Cancer; Penicillin allergy; Stroke; Uterine cancer; Breast cancer (One sister or brother)
Medications: Anti-hypertension; Cholesterol; Other prescription
Medication allergies: None known
Physical Events:
Health Habits (as of 09/19/2006)
BMI: 28.3 (Overweight); 155 lbs
Smoking: Never smoked
Alcohol AUDIT: 0; low risk
Review of Systems
Symptoms Indicated:
Const:
ENT, Eyes:
Resp:
Cardio:
GI:
Uro-gyn:
M/S:
Neuro:
Hemo/Lymph:
Psych:
Endo:
Skin/Hair:

History of Present Illness (as of 09/19/2006)
Chief complaint: Groin, Right leg above the knee
Initial Visit: 01/18/2005
Prior treatments: Physical/Occupational Therapy, Surgery
Red Flags / Considerations
Worsening scores: MCS
Clinical protocols / measures
Patient-reported scores (see graphs on next page)
ODI: 24 (lower = better)
AUDIT:
Physical Function: 45 (Norm: 38)
Role Physical: 32 (Norm: 40)
Bodily Pain: 55 (Norm: 45)
General Health: 46 (Norm: 47)
Vitality: 46 (Norm: 48)
Social Function: 40 (Norm: 47)
Role Emotional: 56 (Norm: 44)
Mental Health: 50 (Norm: 51)
MCS: 52 (Norm: 51)
PCS: 41 (Norm: 40)

	Expectations	Expectation met
Symptoms Relief:		Definitely yes
More Activities:		Not sure
Sleep Better:		Probably yes
Return to Job:		Not applicable
Exercise / Rec:		Not sure

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Longitudinal MCS/PC

Oswestry Disability Index

Activity	Initial Survey (01/18/2005)	This Survey (09/19/2005)
Dressing	no response	1-none
Lifting	no response	4-substantial
Walking	no response	5-severe
Sitting	no response	2-slight
Standing	no response	2-slight
Sleeping	no response	1-none
Social life	no response	4-substantial
Sex life	no response	1-none
Travel	no response	1-none

Longitudinal ODI

Hx & Sx

Patient Perceived Outcomes Benefits

Clinical Status

Oh, by the way ...

- **Dartmouth Spine Center feed forward & feed back data system was exported to 12 other medical centers to gather data for 15 million dollar RCT funded by NIH on spine surgery**
 - **the data system worked flawlessly to collect patient-based & clinician-based data and was then combined with diagnostic tests and cost data streams to generate a powerful data base to study outcomes, costs, and value of care of patients treated medically vs. surgically**
 - **results published in JAMA, NEJM & other publications**
- **Feed forward data system adapted to other DHMC programs: breast cancer, carpal tunnel, geriatrics, vascular, heart failure, etc.**
- **Brian Quinn was “delighted” ... wrote letter to Valley News not knowing that Spine Center was designed based on his ideas**
- **Can now tell patients their “chance of success” for medical vs. surgical treatment based on research on people like them**
- **Data used for program evaluation & improvement & for interdisciplinary research programs – bench to bedside to outcomes**
- **Outcomes & cost data published on DHMC.org website for transparent public reporting**

SPORT SITES...

11states / 13 sites



William Beaumont Hospital
Royal Oak, MI

Washington University
St. Louis, MO

University of California
San Francisco, CA

Dartmouth-Hitchcock Medical Center
Lebanon, NH

Maine
Spine &
Rehab

HJD
NY NY

HSS
NY NY

Rothman Institute
Philadelphia, PA

Nebraska Foundation for
Spinal Research

Rush-Presbyterian-St. Luke's
Chicago, IL

Kaiser Permanente
Oakland, CA

Case-Western
Cleveland, OH

Emory Spine Center
Atlanta, GA

JAMA[®]

The Journal of the American Medical Association

ORIGINAL CONTRIBUTION

Original Contributions

Surgical vs Nonoperative Treatment for Lumbar Disk Herniation: The Spine Patient Outcomes Research Trial (SPORT): A Randomized Trial

James N. Weinstein; Tor D. Tosteson; Jon D. Lurie; Anna N. A. Tosteson; Brett Hanscom; Jonathan S. Skinner; William A. Abdu; Alan S. Hilibrand; Scott D. Boden; Richard A. Deyo

JAMA. 2006;296:2441-2450.

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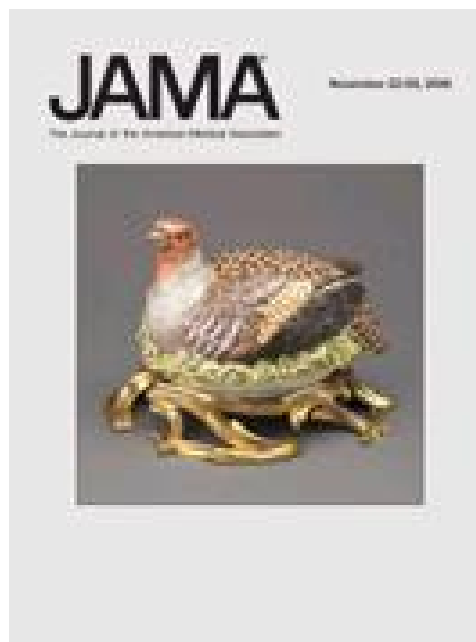
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James N. Weinstein; Jon D. Lurie; Tor D. Tosteson; Jonathan S. Skinner; Brett Hanscom; Anna N. A. Tosteson; Harry Herkowitz; Jeffrey Fischgrund; Frank P. Cammisa; Todd Albert; Richard A. Deyo

JAMA. 2006;296:2451-2459.

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The NEW ENGLAND
JOURNAL of MEDICINE

THE NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Surgical versus Nonsurgical Treatment for Lumbar Degenerative Spondylolisthesis

James N. Weinstein, D.O., Jon D. Lurie, M.D., Tor D. Tosteson, Sc.D.,
Brett Hanscom, M.S., Anna N.A. Tosteson, Sc.D., Emily A. Blood, M.S.,
Nancy J.O. Birkmeyer, Ph.D., Alan S. Hilibrand, M.D., Harry Herkowitz, M.D.,
Frank P. Cammisa, M.D., Todd J. Albert, M.D., Sanford E. Emery, M.D., M.B.A.,
Lawrence G. Lenke, M.D., William A. Abdu, M.D., Michael Longley, M.D.,
Thomas J. Errico, M.D., and Serena S. Hu, M.D.^{*}

4. Convolutions and Solutions (of the mid-range variety)

**Feed Forward and Feedback
“Collaboratories” ... A Model
and Some Complexities,
Impediments and Path Forward**

Source of term “collaboratories”: Schneiderman B. Science 2.0. Science: vm 319
Pg 1349, March 7, 2008.

Convolutions: Some Limitations

- **Vision**: Only a few models and these are not well known
- **Rewards**: Limited incentives to establish collaboratories (at least in a non-CTSA world)
- **HIPPA & Security**: Following patients over time and across settings requires careful attention to privacy and security issues
- **Measurement**: Limited gold standard metrics that are patient-based
- **Standardization**: Resistance to using standard, templated data entry among many clinicians

Solutions = Collaboratories ... for Care, Science & Education

- Patient-centric & professionally organized
- Follow patients over time
- Track health status, diagnoses, treatments over time
- Used for multiple purposes
 - Health Care: to provide better care for patients by matching wants and needs and health status with desired, effective/efficient treatments
 - Health Research: To provide data for observational and prospective research on the causes of disease and disability and on the effectiveness of alternative methods for treating disease and disability
 - Health Professional Education: to create better learning environment – “Good outcomes for good learning and good science for good learning” (David Leach, MD)

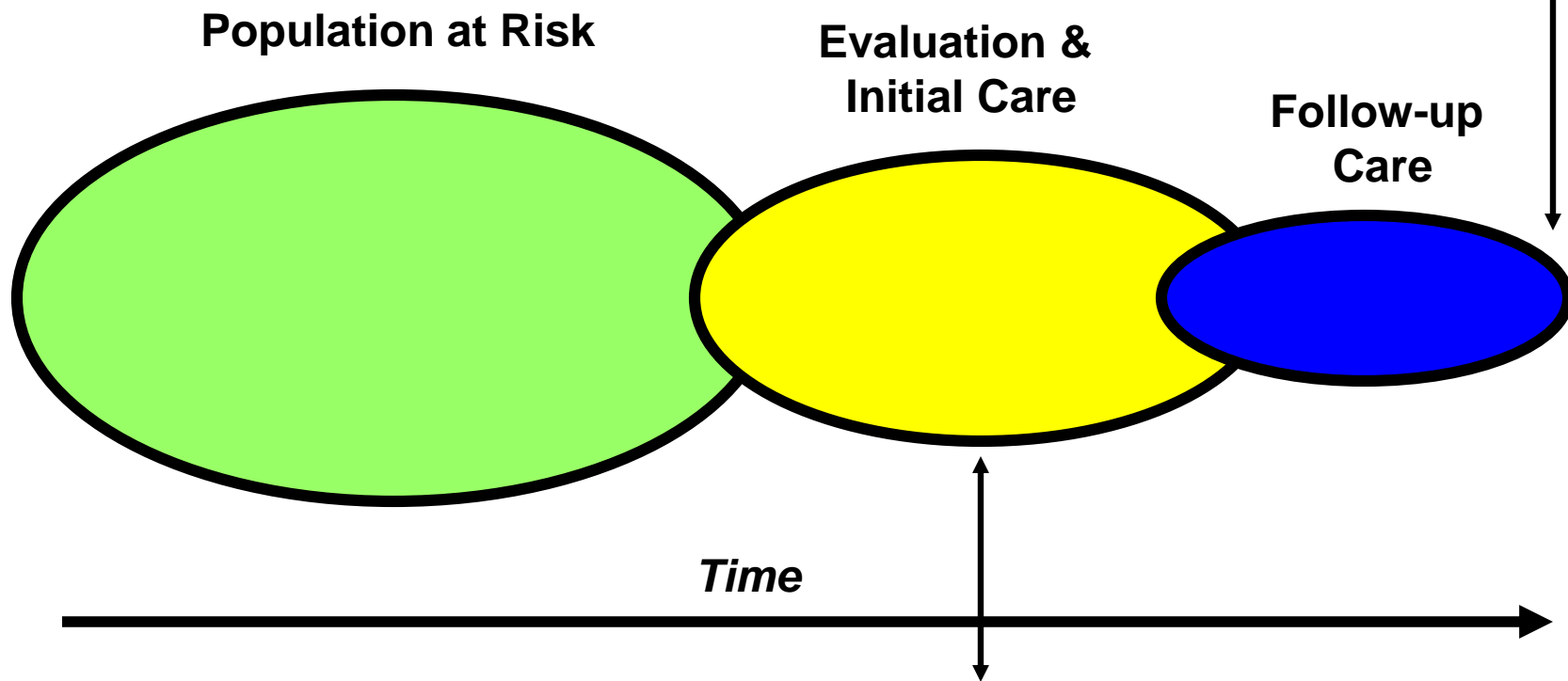
Examples of organizations that have collaboratory features

- **Dartmouth Spine Center and National Spine Center Network**
- **Karolinska Institute & Swedish Rheumatoid Arthritis Registry**
- **Geisinger Health System autism program**
- **Cystic Fibrosis Foundation registry under development**

NQF Measurement Framework: Under Review

Measurement at end of episode:

- Risk adjusted
 - mortality
 - functional status
 - costs of care



Measurement at appropriate times during episode:

- patient factors for risk adjustment
- informed patient preferences aligned with care processes
- symptoms, functional & emotional status

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Opportunity to form collaboratories?

Implications for a “learning” health care system

- “The same underlying information system is required to improve the evidence base for both biotechnology and care delivery. We need to know:
 - Patient attributes and risks (including biologic markers)
 - Specific targeted biologic interventions performed
 - Attributes of system -- delivery methods -- where care provided
 - Health outcomes and costs
- We could then have a truly learning health care system
 - Comparative effectiveness research: *compare biologic interventions*, controlling for patient and system attributes.
 - Comparative performance assessment: *compare systems -- and care delivery methods*, controlling for patient and treatment attributes”

“It’s important to note that clinical work doesn't have to be done at the expense of the academics or scholarly work. They should be and need to be done together.”

**James Weinstein, DO, MS
Chair, Orthopedics
Director, The Dartmouth Institute**

Key Points

- **IOM & WHO definitions of health stressing functioning and well-being requires patient-reported data**
- **Patient-centric health status and health outcomes essential to monitor and improve health care & outcomes**
- **Design feed forward information for patient care, research and education**
- **Patient-centric professionally organized collaboratories can promote this vision**

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