Reframing Health to Embrace Design of Our Own Well-being

Rajiv Mehta & Hugh Dubberly

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Improving health is a “wicked problem”

No consensus on “the problem”

No “stopping rule”

No clear-cut formula for judging solutions

Every solution is a “one-shot operation”

No clear-cut list of alternative solutions

Each person’s situation is unique

—after Horst Rittel

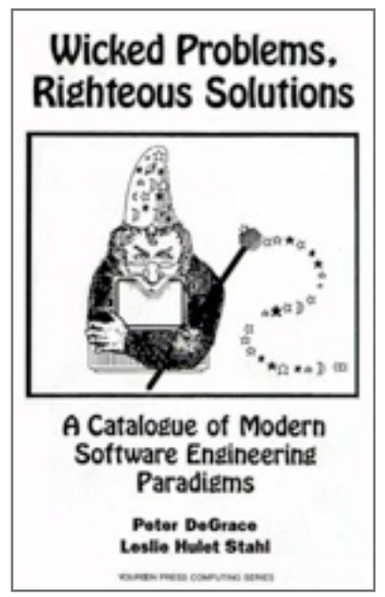
Dilemmas in a General Theory of Planning*

HORST W. J. RITTEL
Professor of the Science of Design, University of California, Berkeley

MELVIN M. WEBBER
Professor of City Planning, University of California, Berkeley

ABSTRACT

Strategy as a Wicked Problem



Wicked Problems, Righteous Solutions

A Catalogue of Modern Software Engineering Paradigms

Peter DeGrace
Leslie Hulet Stahl

Wicked problems can only be resolved by reframing

This talk describes a growing trend, broadening...

health to **well-being**

health-care to **self-management**

the role of **patients** to that of **experiment designers**

What is health?

Traditional frame: illness

Today, health is often seen as the absence of disease or infirmity.

Traditional health-care focuses on acute problems

Goals Eliminate or minimize acute disease and infirmities

↓

Means Medicine and therapies administered by HCPs with patient's consent; patients have little say in means

Health-management focuses on chronic conditions

Goals	Eliminate or minimize acute disease and infirmities	Manage chronic conditions; avoid or slow deterioration leading to acute problems
	↓	↓
Means	Medicine and therapies administered by HCPs with patient's consent; patients have little say in means	Medicine and therapies prescribed by physicians and administered by patients, who may have other priorities or may reject means

Behavior does not change on a physician's orders

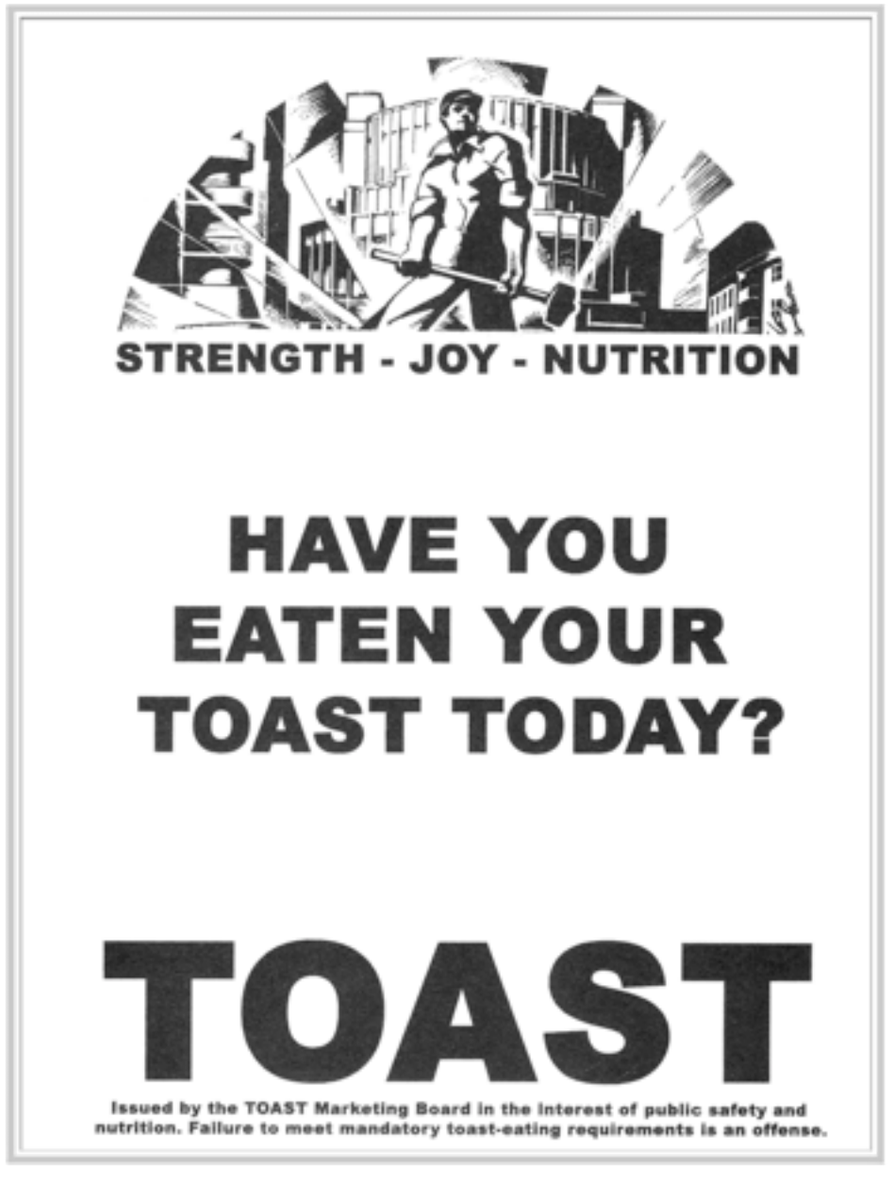
"Take medication as directed"

"Walk 10,000 steps"

"Get 8 hours of sleep"

"Snacks/sweets only on days beginning with S"...

Result: poor compliance



Pathology-focused solutions fail to see the whole person

Narrow focus on
asthma, CHF, or diabetes,...

Pill reminders

Trackers for diet, exercise, mood, pain...

Bio-metric devices...

Result: modest impact

HCP-patient relationships are not symmetrical

We call individuals **patients**

Doctors and nurses are **professionals**

Professionals **care for** patients

Patients passively receive **treatment**

Patients who do not follow a **physician's orders** are not **in compliance**

In wicked problems, we share a “symmetry of ignorance” —Horst Rittel

The tools of acute-care are ill-suited to chronic-care

The American Heart Association reports, "**The No. 1 problem in treating illness today is patients' failure** to take prescription medications."

That's blaming patients.

Leonard Syme suggests, "**We need to pay attention to the things people care about**, and stop being such experts about our risk factors."

Reframing: Well-being

Health is a state
of complete physical,mental,
and social well-being
and not merely the absence
of disease or infirmity.

—World Health Organization (WHO),1948

Health is “a resource for life, not the objective of living”

—World Health Organization (WHO), 1986

Well-being depends on more than health-care

Goals Health: complete physical, mental and social well-being

Means Acute care Chronic care Self-management supported by HCPs, friends, and family

Other means, such as:
- Employer practices
- Social policies
- Essentials:
  clean air + water
  food + shelter
  education + stability

Well-being is a means, not an end

Goals Quality of everyday living

Means Health: complete physical, mental and social well-being

Means Acute care

Chronic care

Self-management supported by HCPs, friends, and family

Other means, such as:
- Employer practices
- Social policies
- Essentials:
  clean air + water
  food + shelter
  education + stability

Other goals/means, such as:
- Love of family + friends
- Valued work
- Financial security
- Physical security
- Participation in society
- Fun + joy

What is self-management?

Goals Quality of everyday living

Means Health: complete physical, mental and social well-being

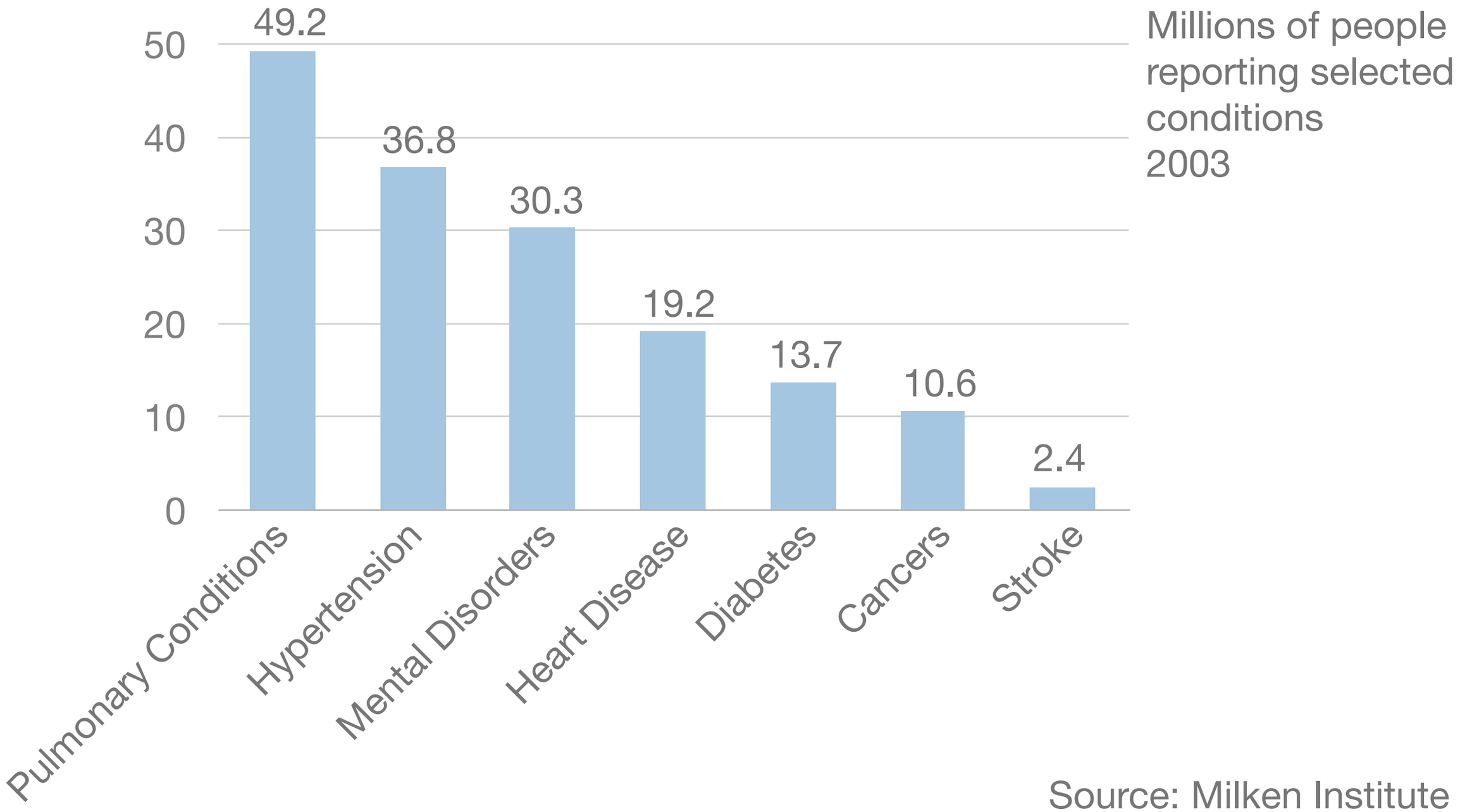
Means Acute care | Chronic care | Self-management supported by HCPs, friends, and family

Means Medicines + therapies | Medicines + therapies | People actively involved in their own:
- monitoring...
- goal-setting...
- experimenting...
- understanding...
- reflecting...

...in relation to their:
- bodies
- diet
- activities
- relationships
- environment

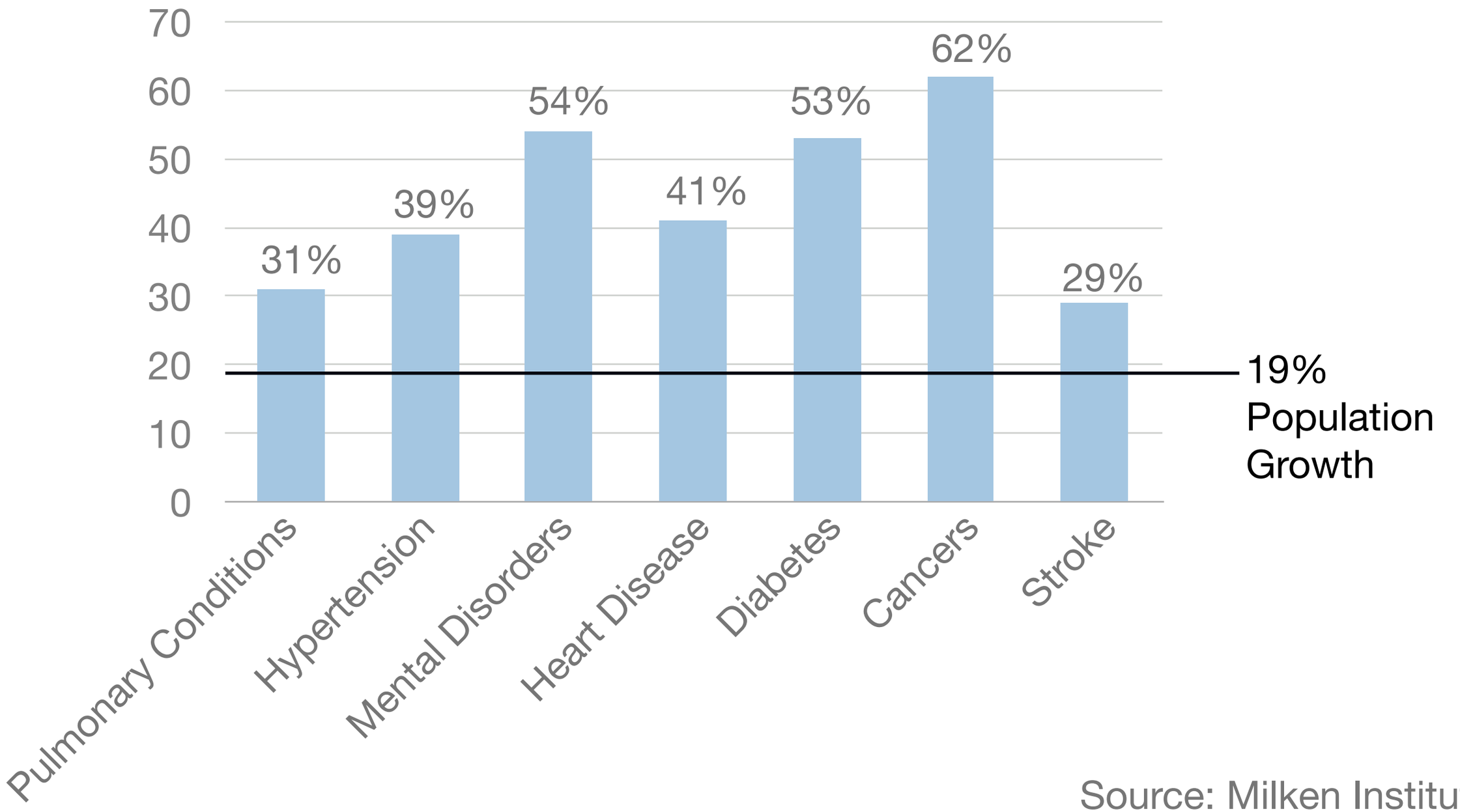
Some data

The norm: complex self-management



Source: Milken Institute

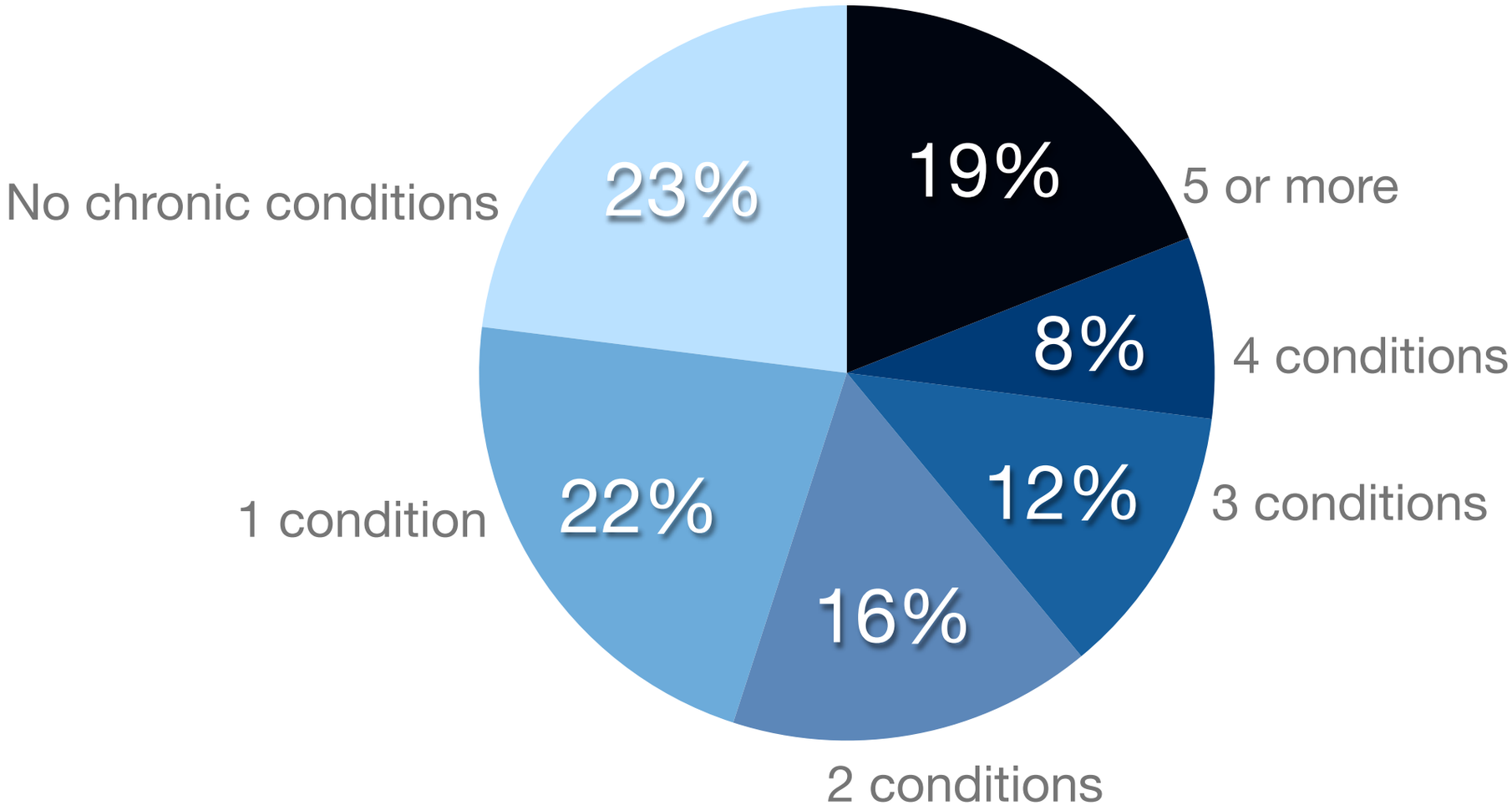
Projected rise in chronic disease from 2003 to 2023



Source: Milken Institute

Chronic health conditions are often interrelated

A survey of 120,000 employees found:

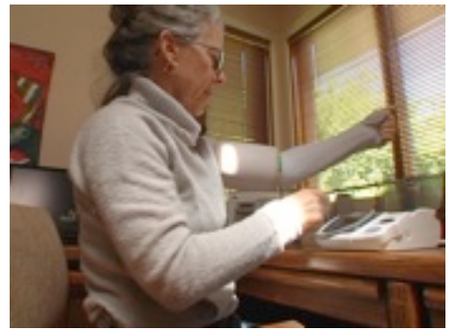


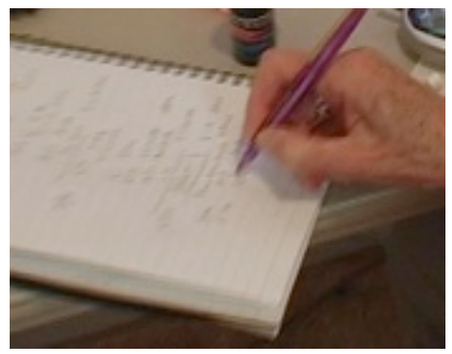
Source: IBI

Making this real

People care about Life ...

… and cope with Health





Diabetes

~24m adults have diabetes (mainly type 2)
~10m have 1 additional chronic illness
~ 6m have 2 or more additional chronic illnesses

Medications

Insulin Novolin
Insulin Novolog
Metformin
ACE inhibitor
Multi-vitamin
Ibuprofen

Therapies

Foot massage

Biometrics

Blood glucose
Blood pressure / pulse
Weight

Exercise

Various

Diet

Food journal
Calorie counting

Health Status

Physical Symptoms

Fatigue
Frequent urination
Excessive thirst
Sudden weight loss
Blurred vision
Cold sweat
Headache

Psychosocial Health

Mood
Anxiety
Stress
Overall Health

Medication Notes

Side effects, such as...
Injection site pain/redness/swelling
Rash
Shortness of breath

Context

Social

Activities
Social interaction

Work

Workload
Work conditions

Geographic

Location
Environmental stressors

Crohn's Disease

~500,000 adults

Medications

Humira
Azathioprine
Bupropion (depression)
Folic Acid
Vitamin B12
Calcium + Vitamin D

Therapies

Relaxation exercises

Biometrics

Weight
Temperature (as needed)

Exercise

Yoga
Walking

Diet

Meticulous food journaling

Health Status

Physical Symptoms

Fatigue
Nausea
Loss of appetite
Abdominal Pain
Diarrhea
Bloody Stools
Rectal Bleeding

Psychosocial Health

Mood
Anxiety
Stress
Overall Health

Medication Notes

SIDE EFFECTS
Injection site pain/red/swelling
Rash
Shortness of Breath
Joint pain
CONTRA-INDICATIONS
Cold or Sinus Infections

Context

Social

Activities
Social interaction

Work

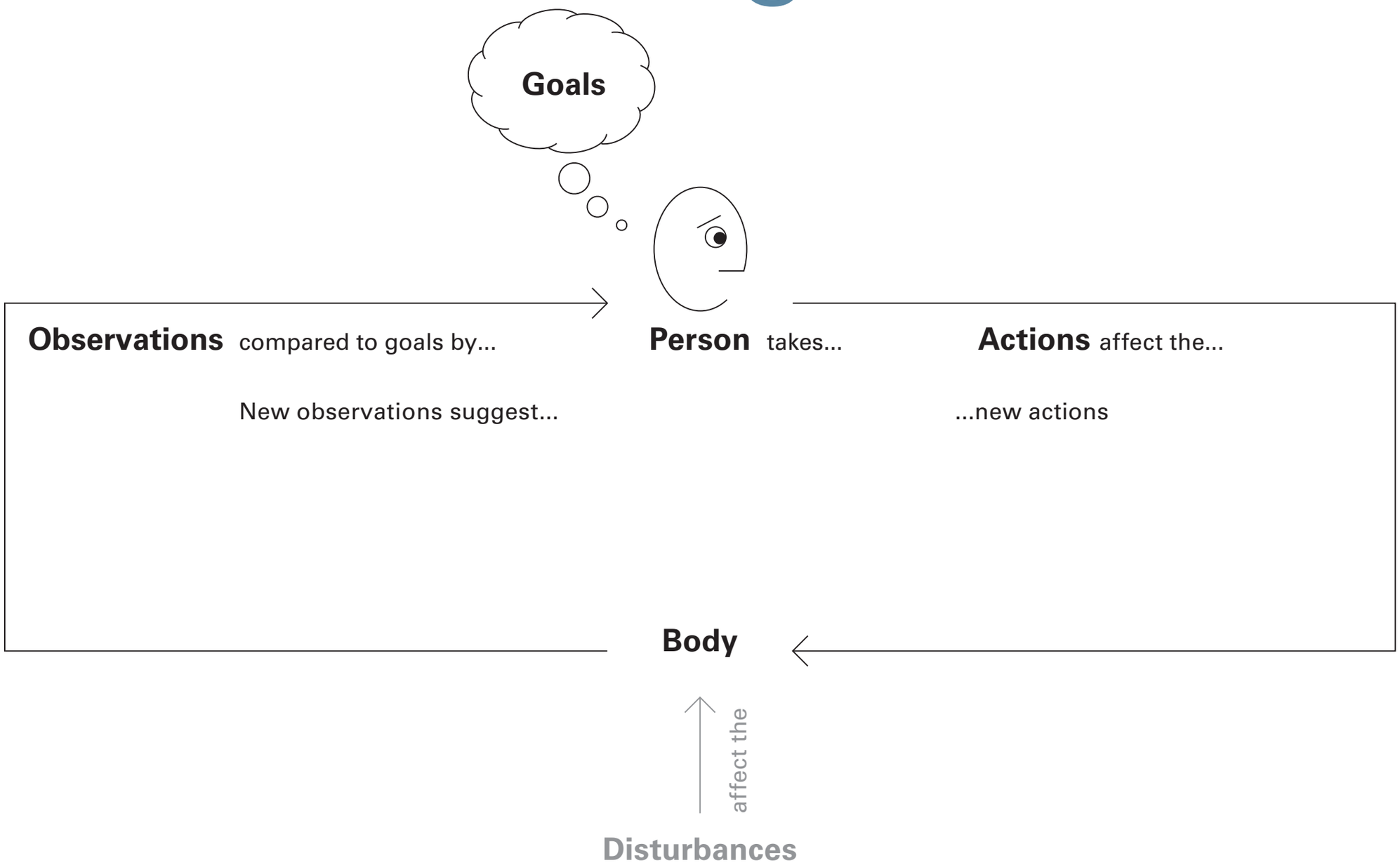
Workload
Work conditions

Geographic

Location
Environmental stressors

Implications for design

A billion little experiments: each of us figuring out what's working for us now



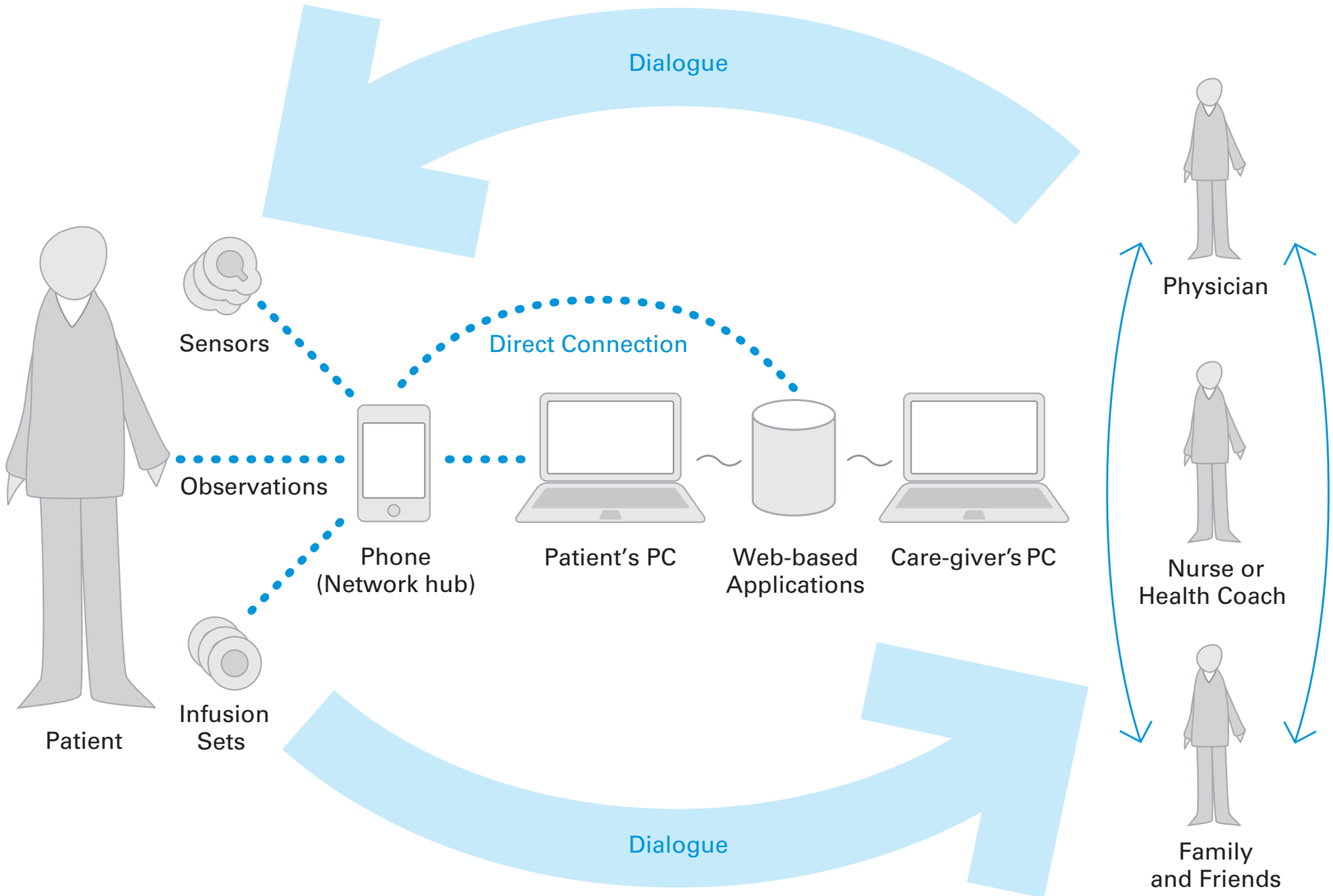
trial and error ≈

experiment ≈

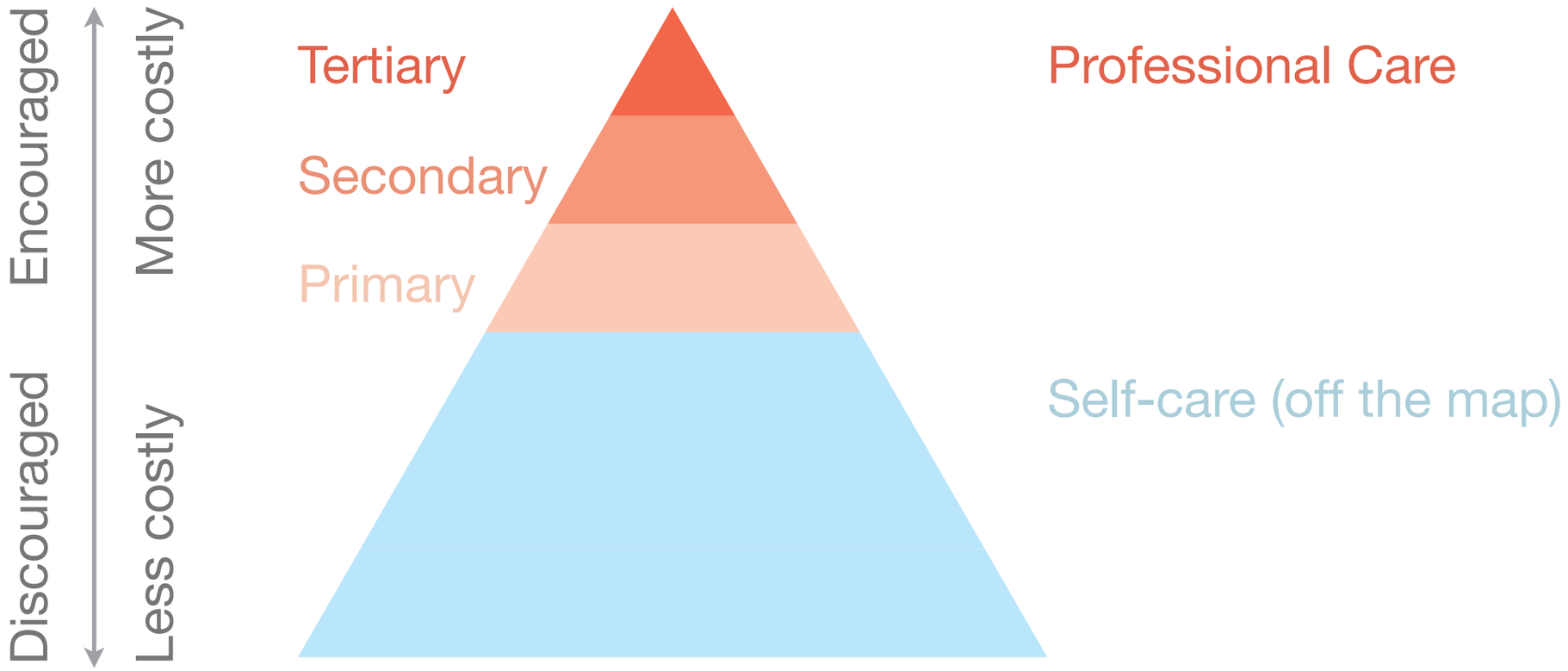
quality management ≈

≈ design

An enabling infrastructure: sensors+big data+services

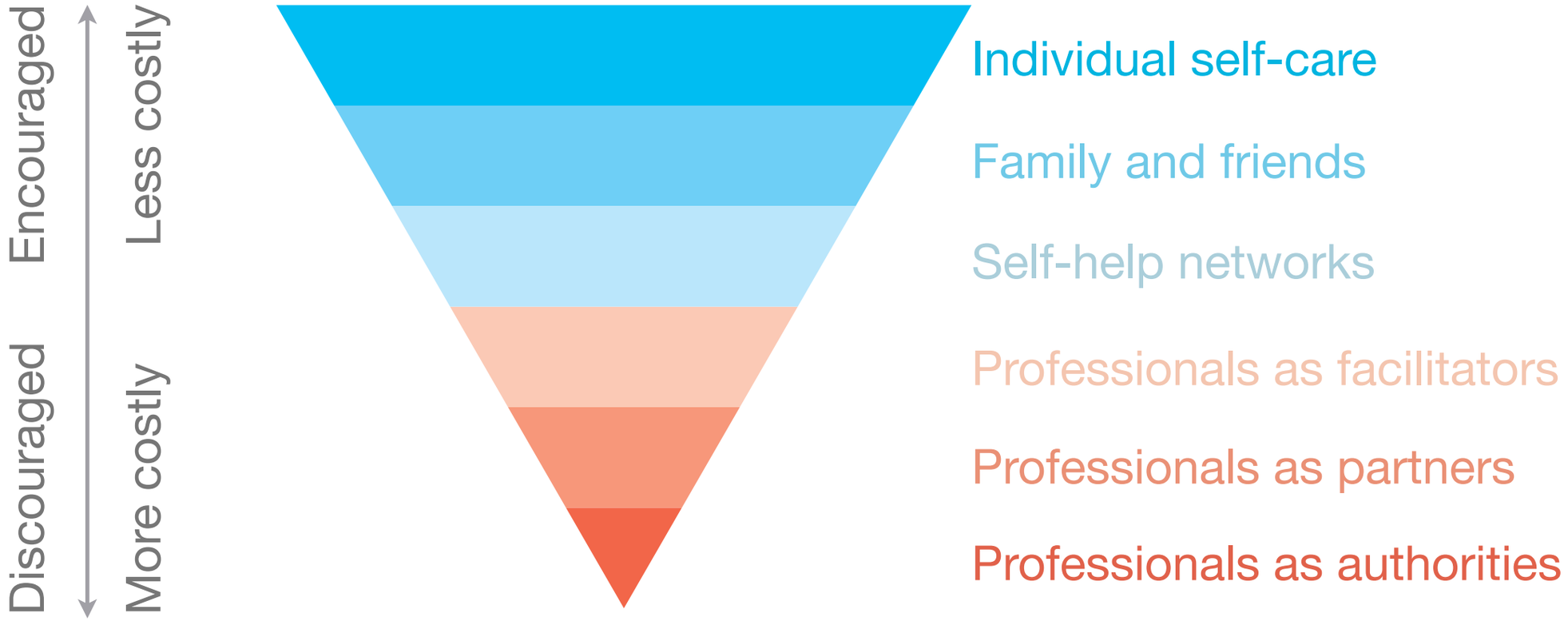


Industrial Age Medicine



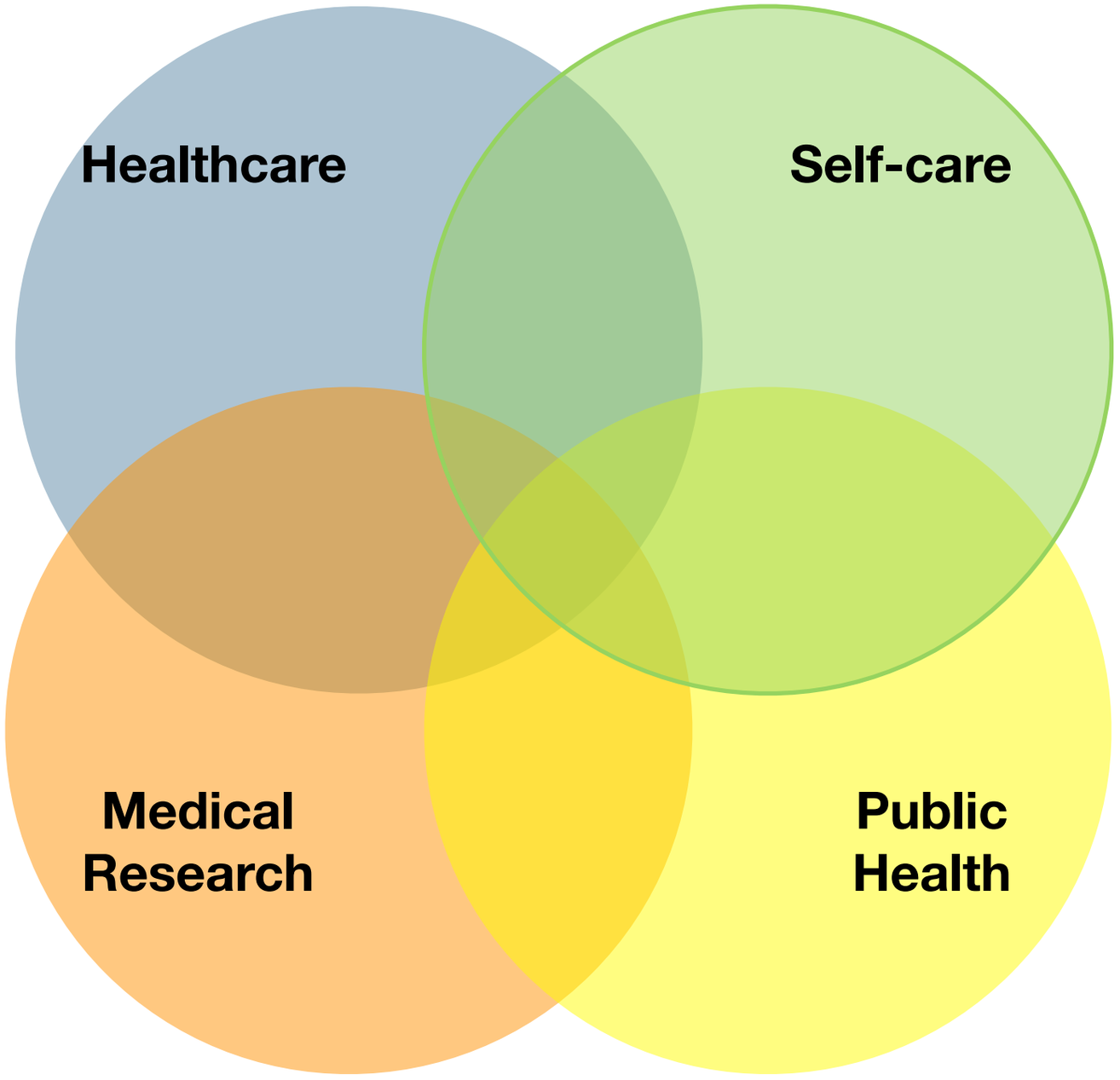
Source: Tom Ferguson, 1995

Information Age Health-care



Source: Tom Ferguson, 1995

Recognizing a 4th distinct and legitimate health sphere



Patient-driven health-care

"A collaborative co-care model is starting to evolve for health-care delivery... **the patient's role may become one of active participant, information sharer, peer leader, and self-tracker,** while the physician's role may become one of care consultant, co-creator, and health co-ordinator."

—Melanie Swan, *International Journal of Environmental Research and Public Health*, 2009

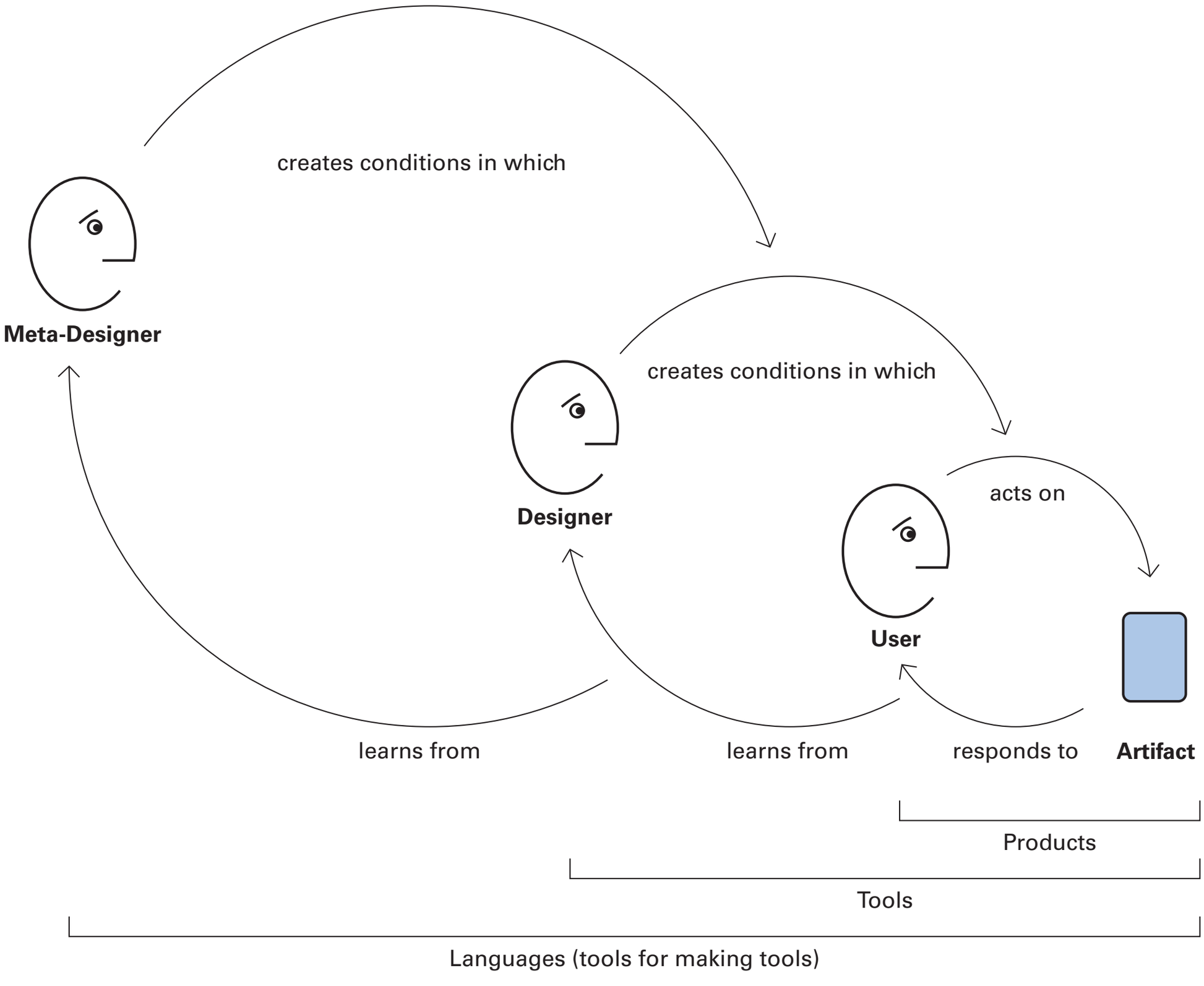
Health frame eras summary

	Traditional **Health-care frame**	**Emerging** **Self-management frame**
Scope	Relieve acute conditions Now	Maintain well-being Over a lifetime
Approach	Intervention; treatment Expert-directed Apply standards of care Lengthy regulatory pre-approval	Prevention; healthy living Self-managed Measure, assess, and adjust; iterate Learn and adapt as you go
Subject	Symptoms and test results	Whole person, seen in context
Response	Prescribe medication	Improve behavior, environment

…summary continued

Relies on	Medical establishment	Individual, family, and friends Social networks, others like me
HCP as	Authority, expert Dispensing knowledge	Coach, assistant Learning from patients
Patient as	Helpless, child-like Taking orders	Responsible adult Setting goals, testing hunches
Relation	Asymmetric, one-way Command and control	Symmetric, reciprocal Discussion and collaboration
Records	HCP’s notes of visit Sporadic Dispersed between offices Managed by HCPs	Patient’s notes, data from sensors Continuously collected Connected; aggregated Controlled by patients

Patients become designers



As you
design / market / deploy
self-management
technologies ...

Questions to ask yourself

People focus on life, not health

Are you framing the problem broadly enough?

- Understand full context of person's life, not just the micro-activity (e.g. taking a pill, recording weight)

Is your system alleviating or increasing the user's workload?

- Minimize bio-cost of initiating and using self-management tools

Whose needs are you addressing first and foremost?

- Appreciate centrality of self-directed goals; user as final authority of personal goals and deciding "what's best"

Health is multi-factorial

How well are you addressing the user's unique situation?

Is your system supporting all key factors,
including non-medical factors?

- Design flexible frameworks,
  customizable by users to their own needs

- Accommodate, don't dictate, user's choice
  of tools, therapies, interests

- Enable people to design their own well-being

Health is dynamic

Is your system meant for on-going or episodic use?

Is it designed to evolve?

- Design for ongoing, constantly changing, tiny self-experiments
- Support control and tracking of non-experimental variables

Continuous learning enables continuous adjustment

To what extent does your system support self-learning?

- Provide auto-analysis of user's own health experience over time
- Support user self-analysis (e.g. visualization)

How does your system enable learning from others' experience?

- Support learning from "others like me"
- Support auto-identification of "others like me"

Special thanks to: Paul Pangaro & Shelley Evenson

Full paper at: http://bit.ly/ReframingHealth-Paper

Also: “A Billion Little Experiments” http://bit.ly/BillionExperiments

Rajiv Mehta

rajivzume@gmail.com

650 823 3274

Hugh Dubberly

hugh@dubberly.com

415 468 9799