Reframing Health as more than Health-care

Recognizing the importance of self-management and the role individuals have in designing their own well-being

Rajiv Mehta & Hugh Dubberly

Improving health-care 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

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**

This trend parallels a shift in design practice, enabling...

users to be **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

      ↓

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

Manage chronic conditions; avoid or slow deterioration leading to acute problems

      ↓

Medicine and therapies prescribed by physicians and administered by patients, who may have other priorities or may reject means

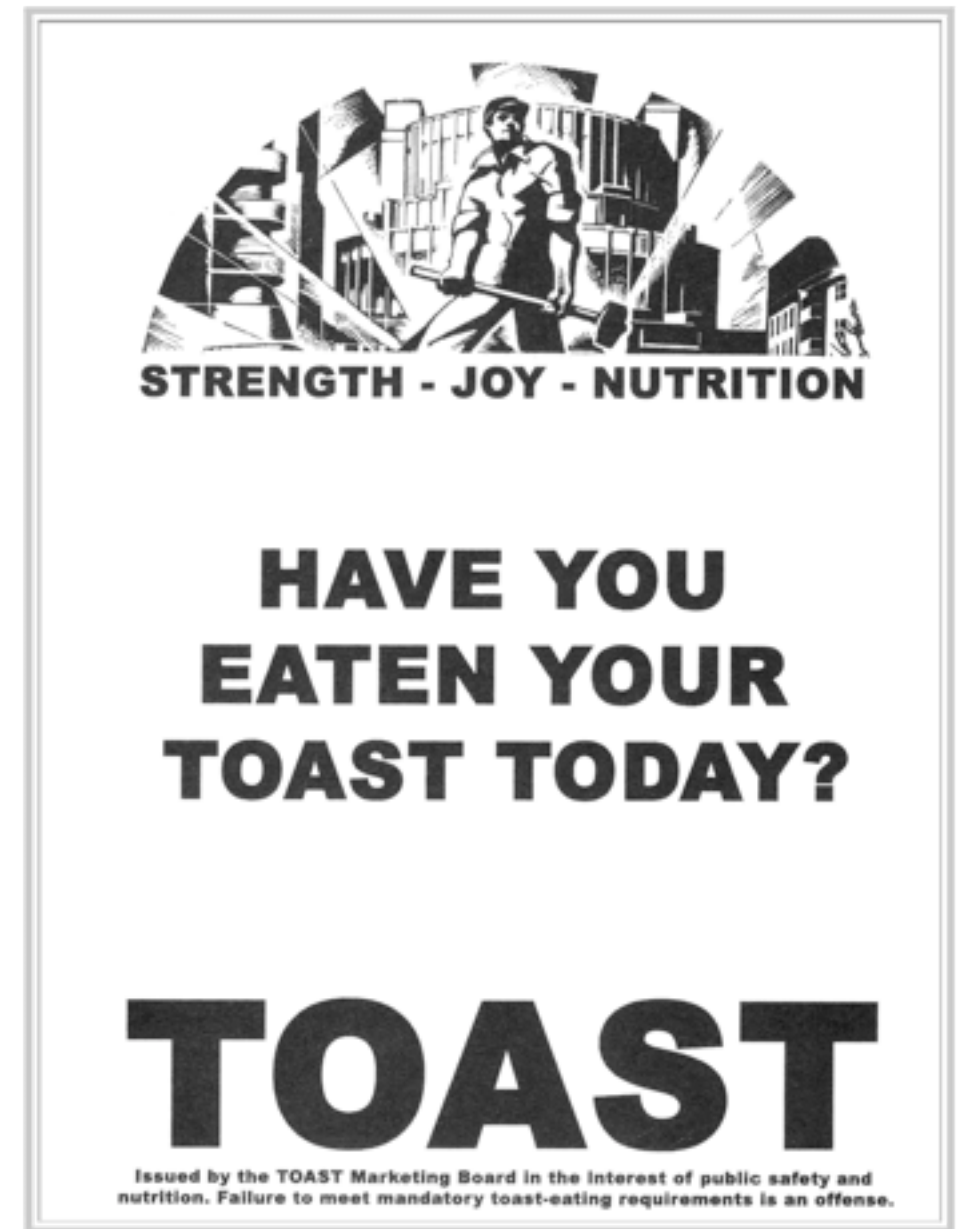# Behavior does not change on a physician's orders

"Take medication as directed"

"Walk 10,000 steps"

"Get 8 hours of sleep"

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

Result: poor compliance

STRENGTH - JOY - NUTRITION

HAVE YOU EATEN YOUR TOAST TODAY?

TOAST

Issued by the TOAST Marketing Board in the interest of public safety and nutrition. Failure to meet mandatory toast-eating requirements is an offense.

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 risk factors."

Reframing: Well-being

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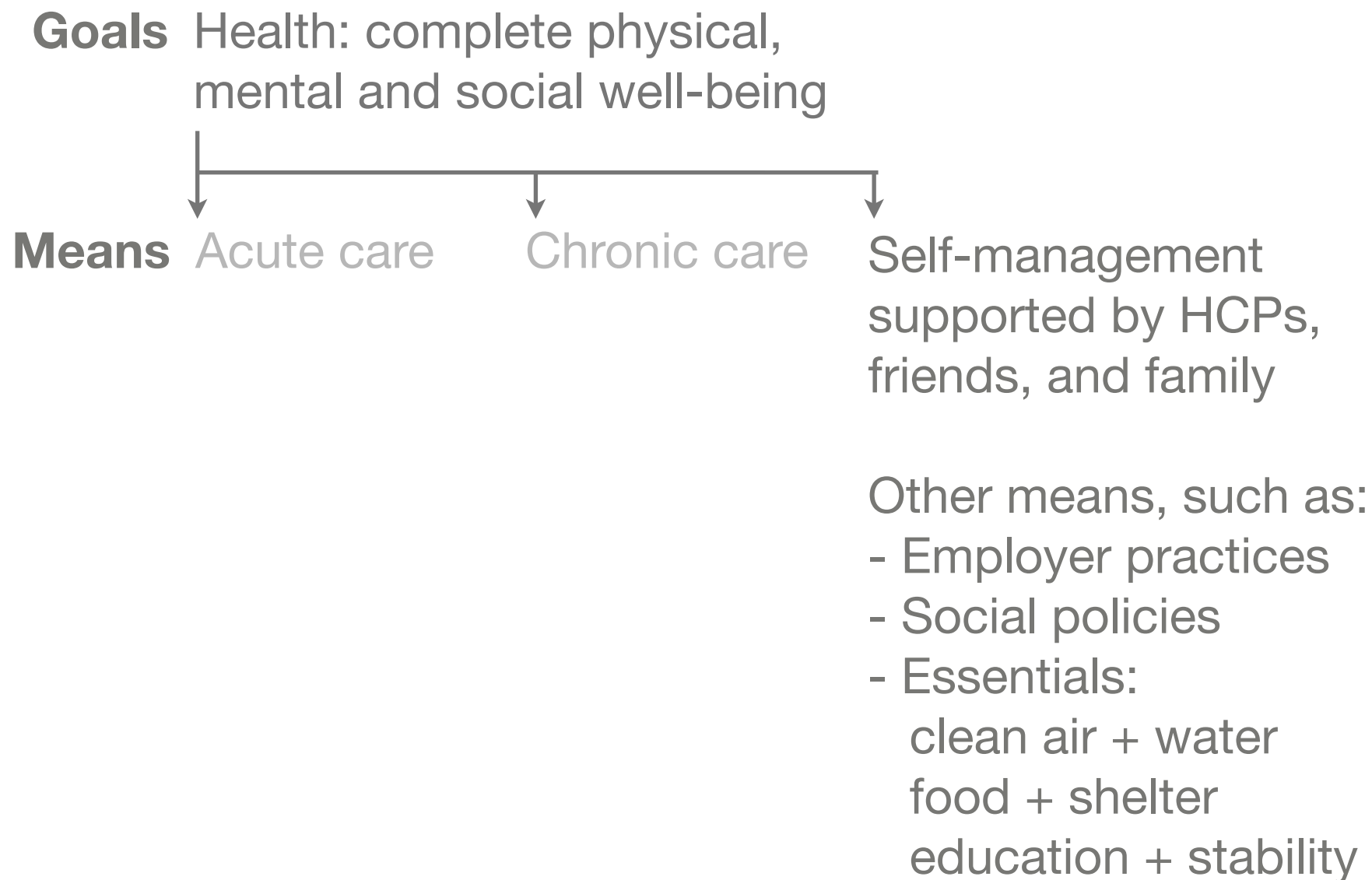and not merely the absence
of disease or infirmity.

—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
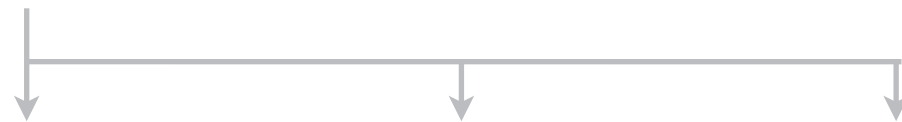 education + stability

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

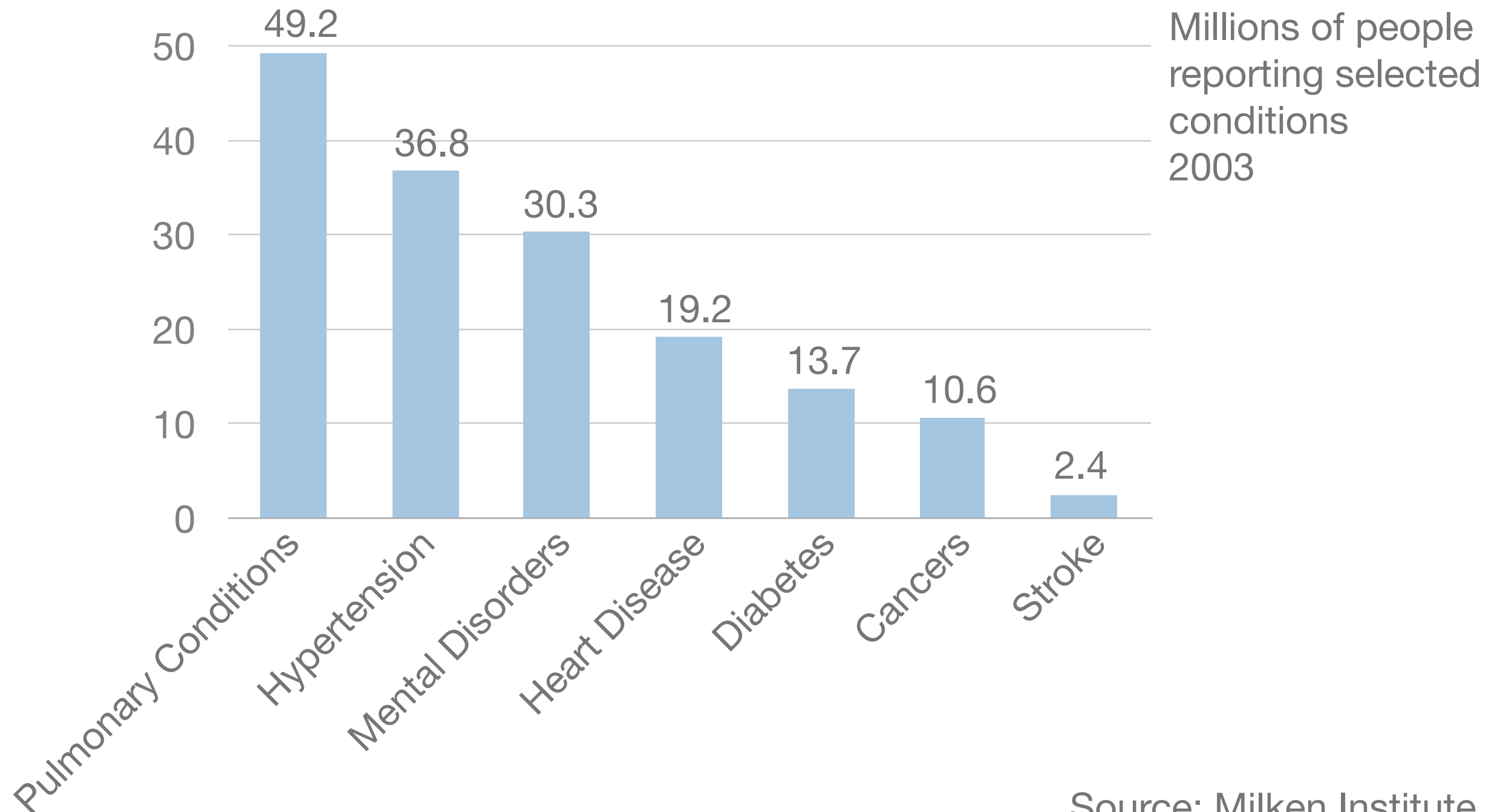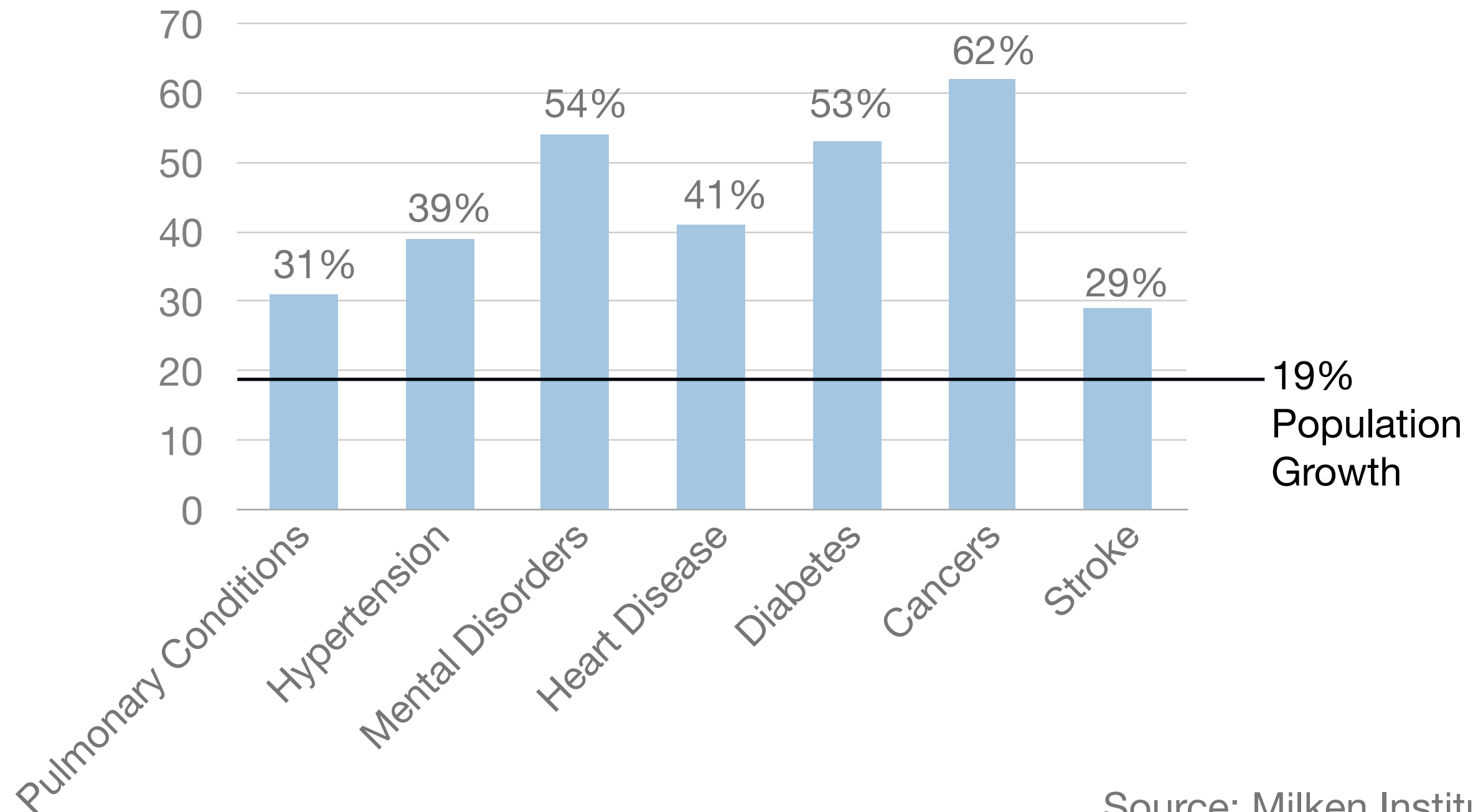| **Means** Medicines + therapies	Medicines + therapies	People actively involved in their own: - monitoring... - goal-setting... - experimenting... - understanding... - reflecting...	...in relation to their: - bodies - diet - activities - relationships - environment

Some data

The norm: complex self-management

49.2
36.8
30.3
19.2
13.7
10.6
2.4

50
40
30
20
10
0

Pulmonary Conditions
Hypertension
Mental Disorders
Heart Disease
Diabetes
Cancers
Stroke

Millions of people reporting selected conditions 2003
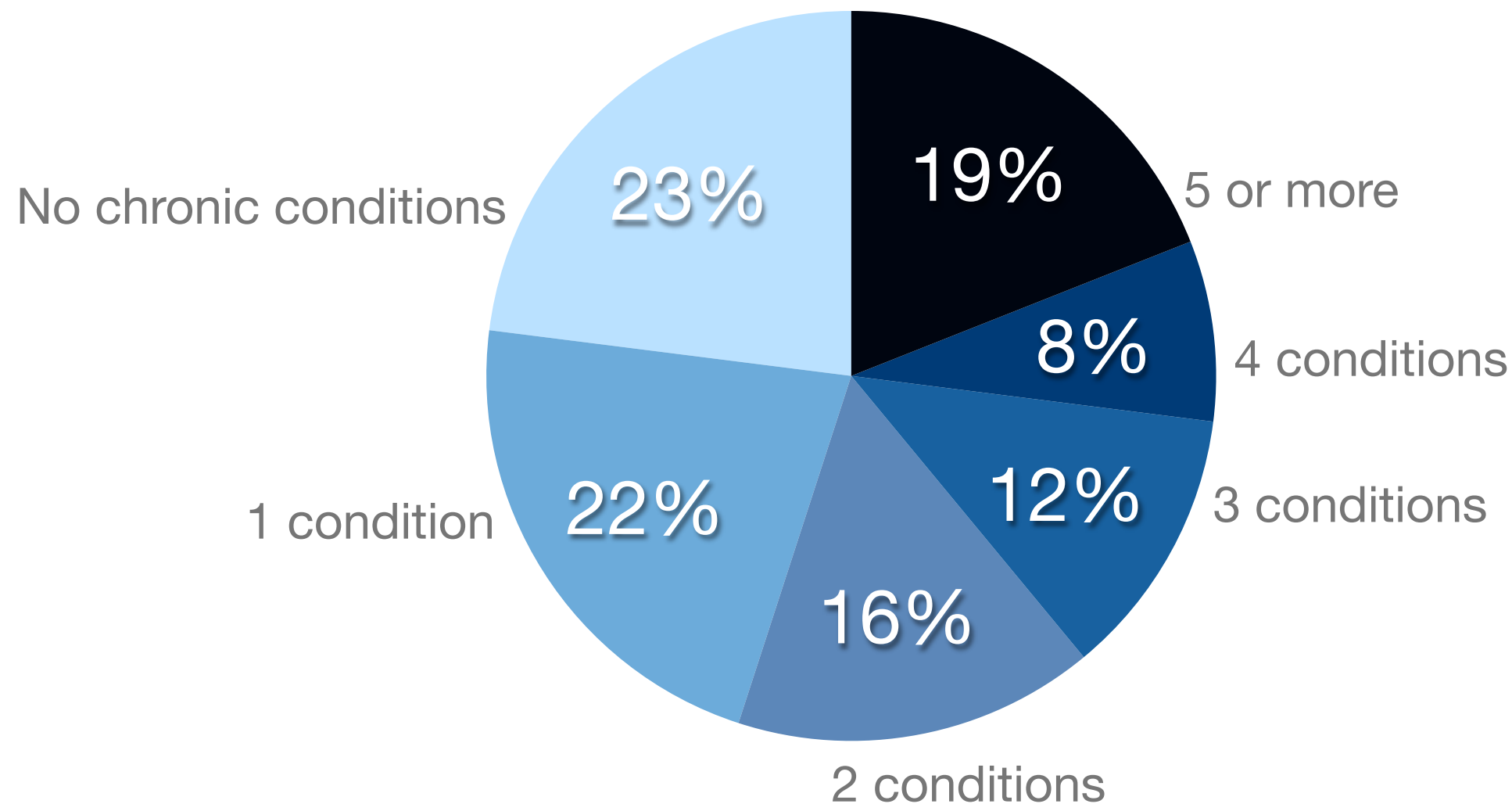
Source: Milken Institute

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:

No chronic conditions — 23%

5 or more — 19%

4 conditions — 8%

3 conditions — 12%

2 conditions — 16%
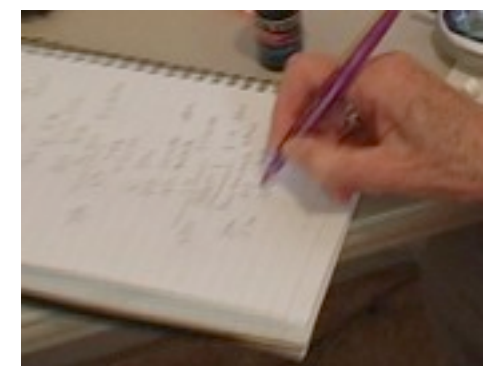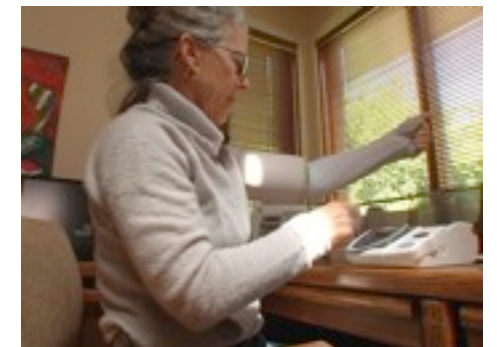
1 condition — 22%

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

Chron'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
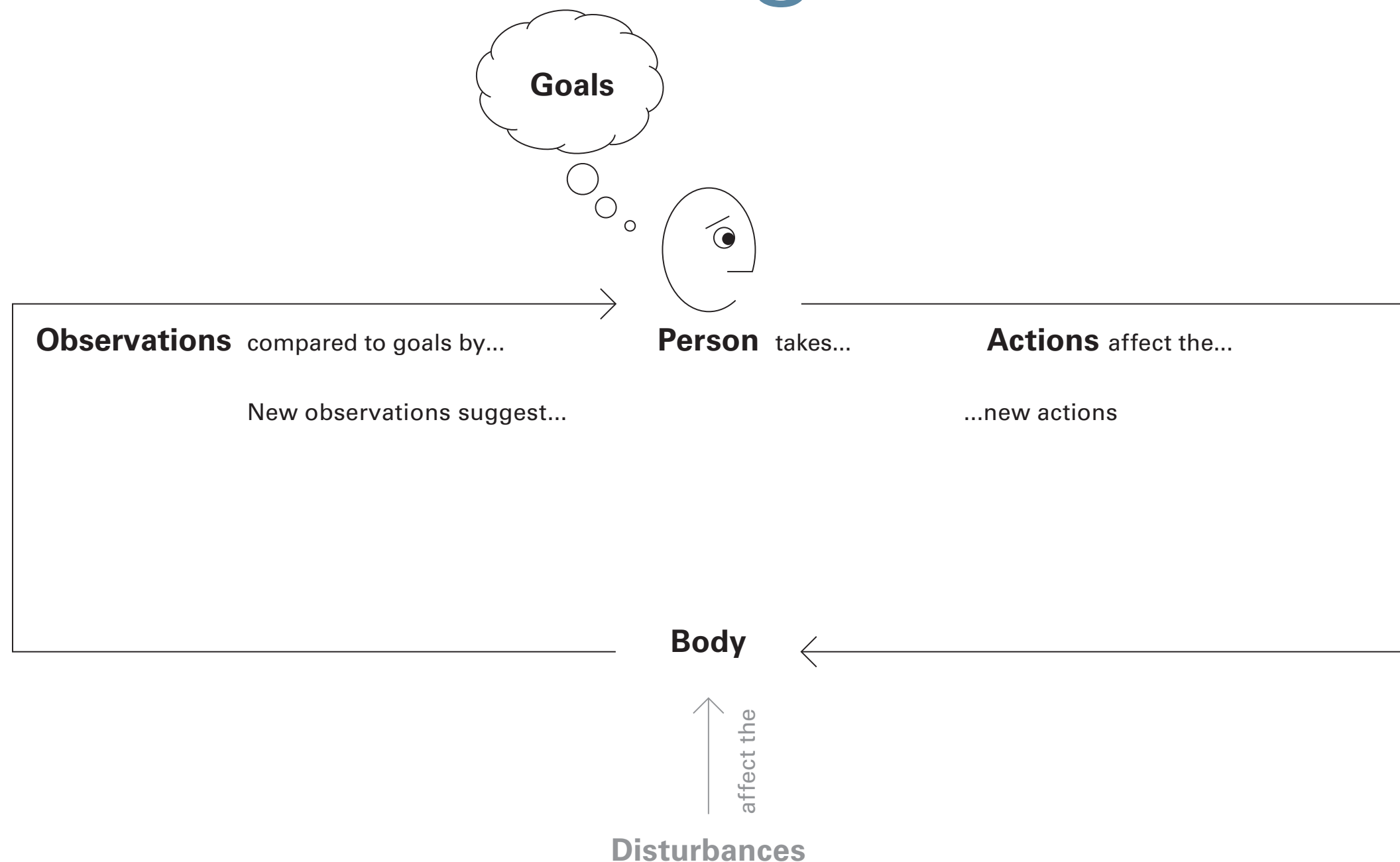Social interaction

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

Goals

Observations compared to goals by...

New observations suggest...

Person takes...

Actions affect the...

...new actions

Body

affect the

Disturbances

trial and error ≈
experiment ≈
quality management ≈
≈ design

An enabling infrastructure: sensors+big data+services

Dialogue

Sensors

Direct Connection

Observations

Phone (Network hub)

Patient's PC

Web-based Applications

Care-giver's PC

Infusion Sets

Patient

Dialogue

Physician

Nurse or Health Coach

Family and Friends
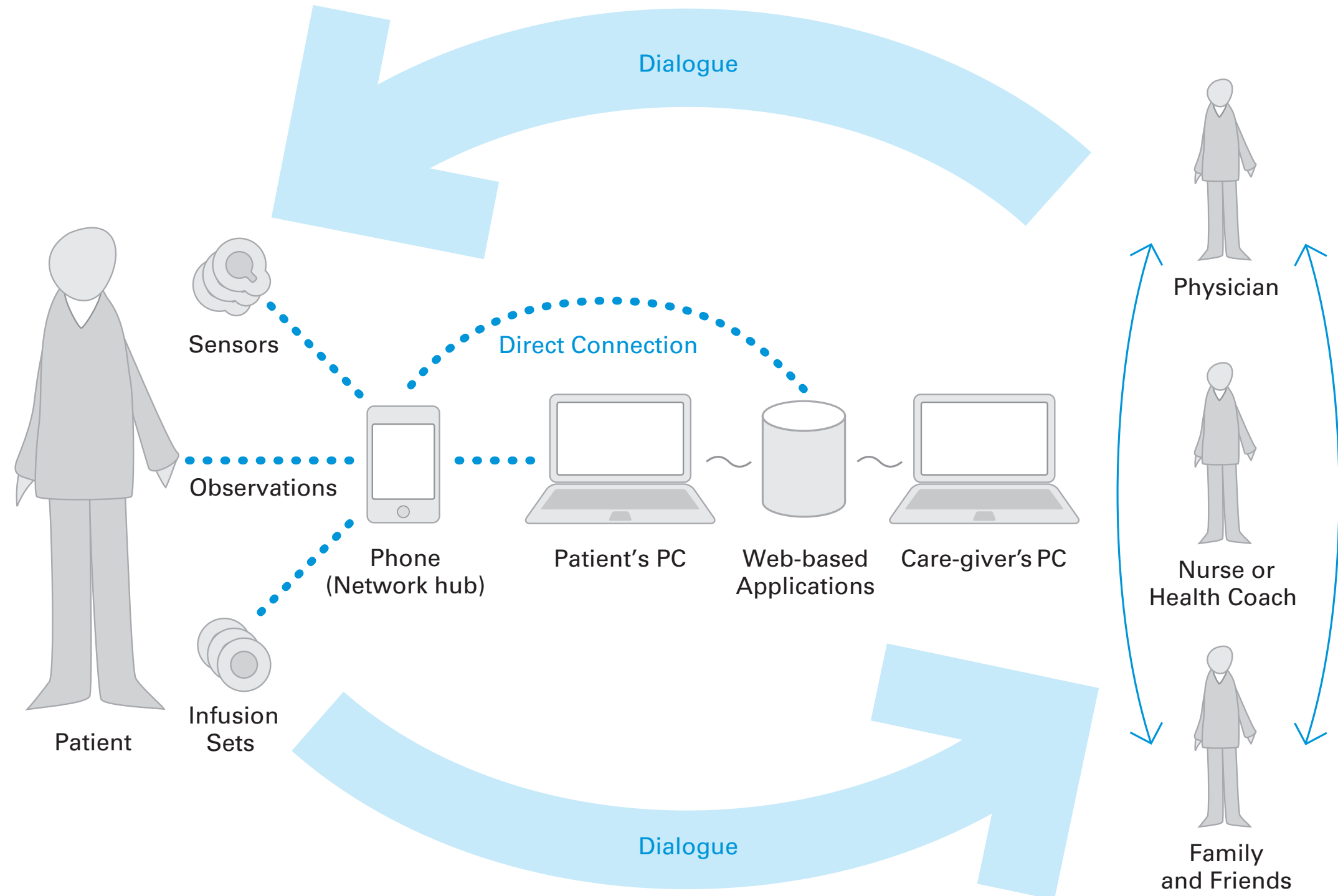
Industrial Age Medicine

Tertiary

Secondary

Primary

Professional Care

Self-care (off the map)

Encouraged / More costly

Discouraged / Less costly
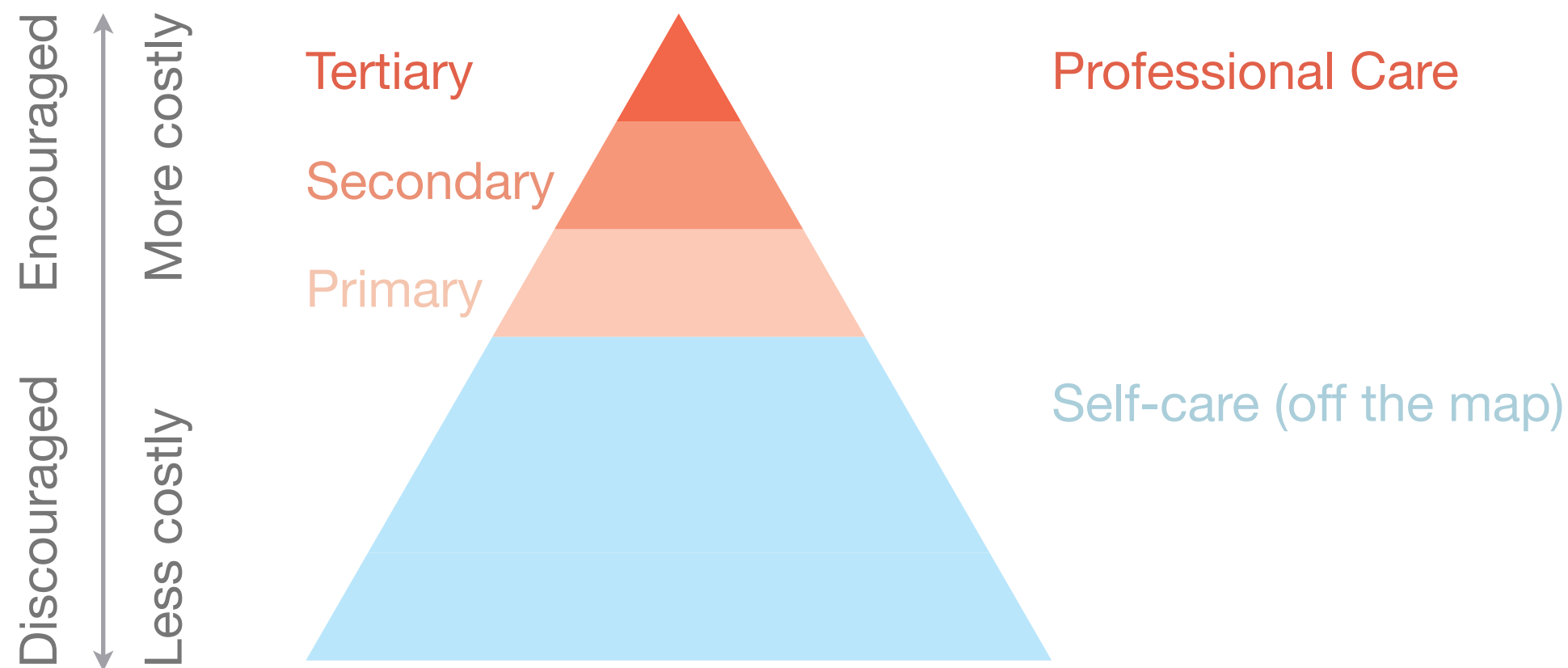
Source: Tom Ferguson, 1995

Information Age Health-care

Encouraged — Less costly

Discouraged — More costly

- Individual self-care
- Family and friends
- Self-help networks
- Professionals as facilitators
- Professionals as partners
- Professionals as authorities
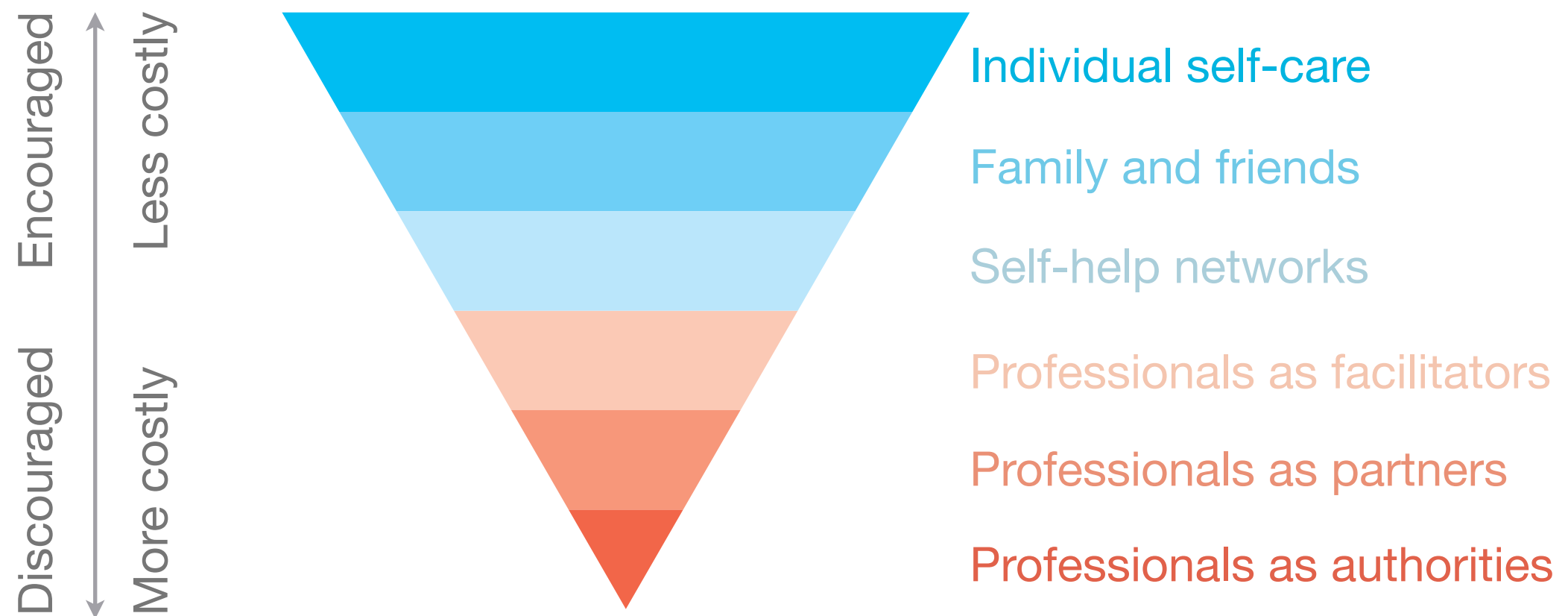
Source: Tom Ferguson, 1995

Convergence for health

Biology   **Computing**
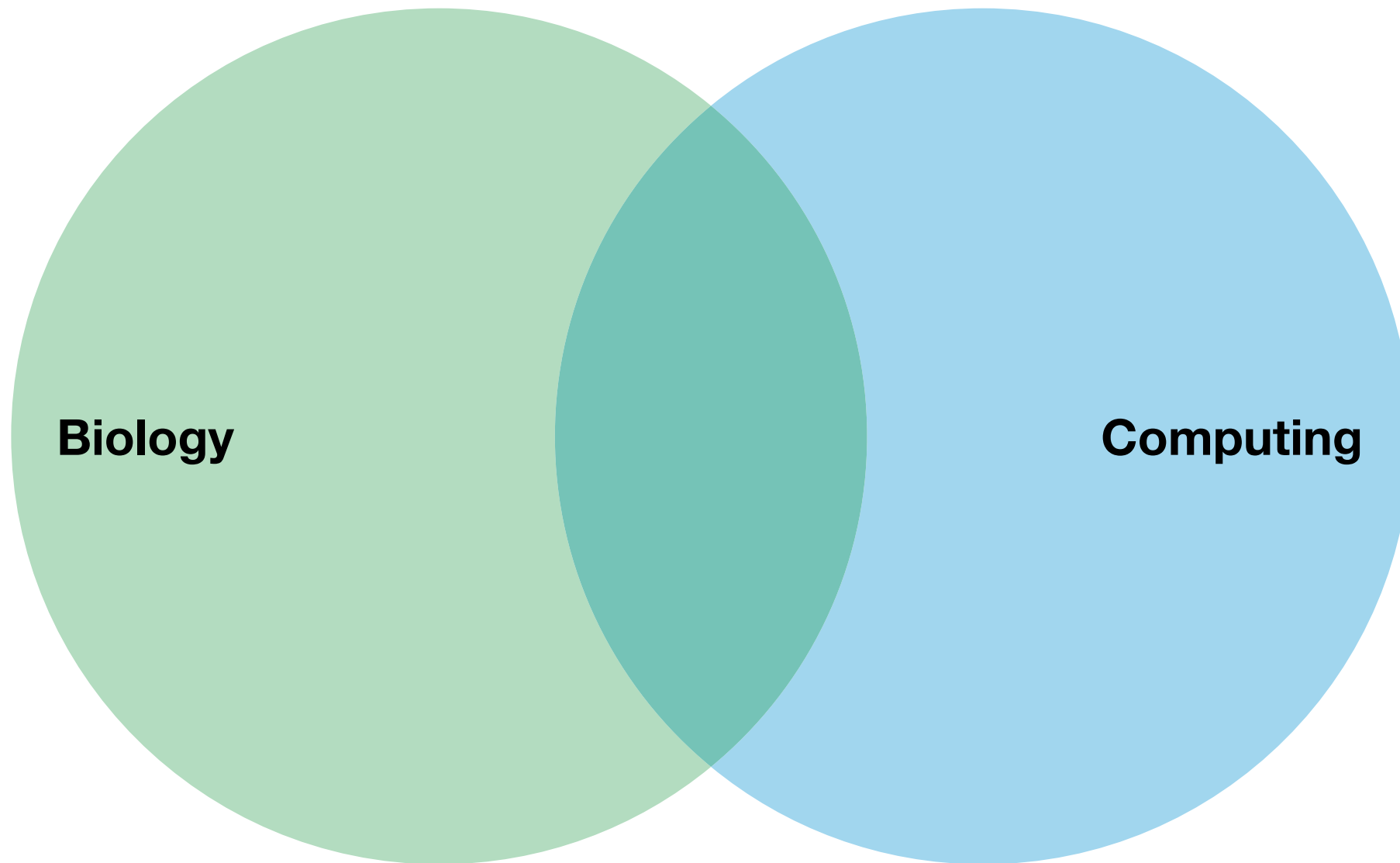
Patient-driven health-care

"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

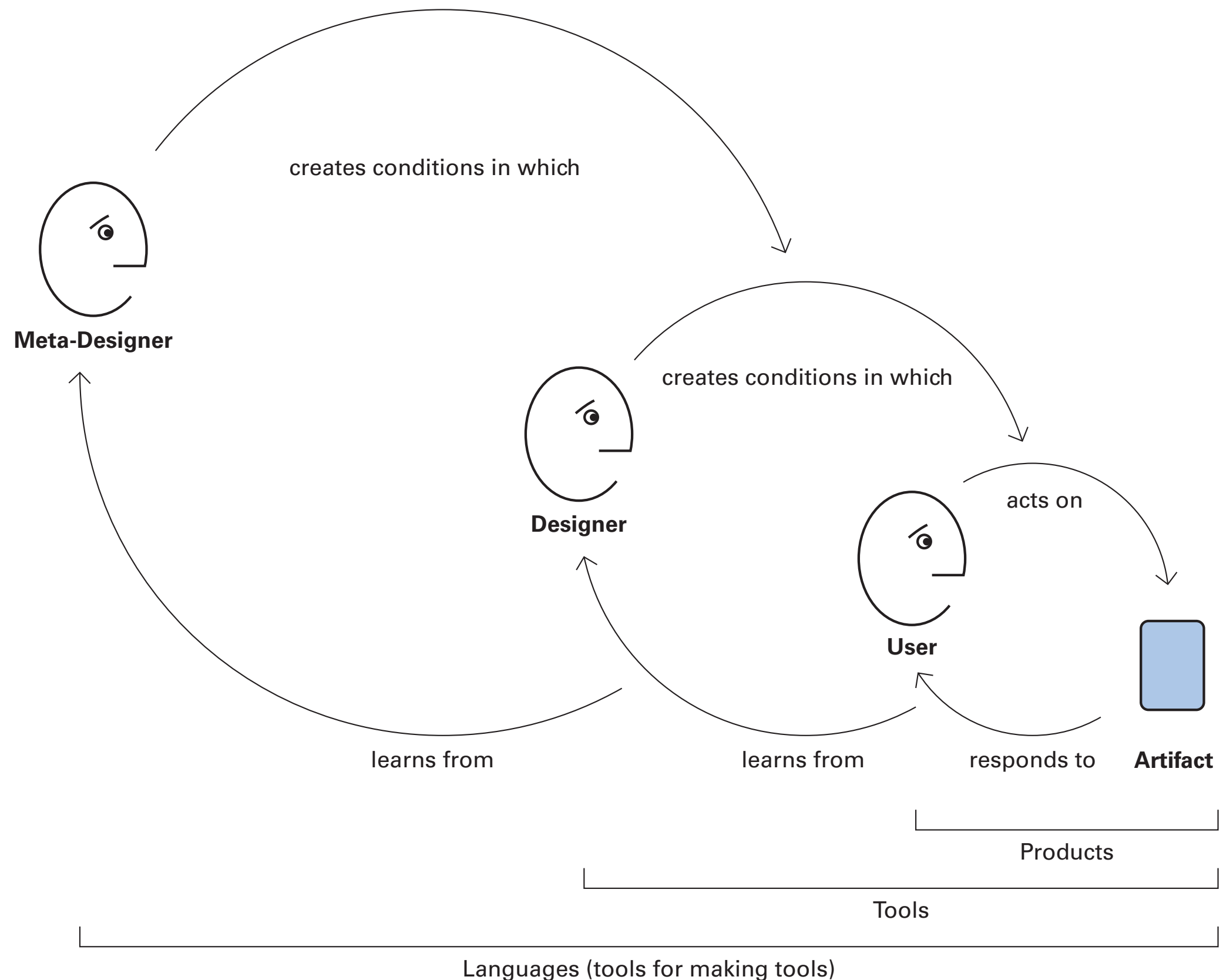|	**Traditional Health-care frame**	**Emerging Self-management frame**
Scope	Relieve acute conditions Now	Maintain well-being Over a lifetime
Approach	Intervention; treatment Expert-directed Apply standards of care Lengthy regulatory pre-approval	Prevention; healthy living Self-managed Measure, assess, 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

Design frame eras summary

	Traditional Designer frame	Emerging Meta-designer frame
Scope	Stand-alone products	Integrated systems of hardware, software, networked applications, and human services
	Manufactured, duplicated	Configured, customized
	Single-function tools	Languages, platforms, APIs, construction kits, kits of parts
Function	Aid consumption	Aid production
Approach	Simplify Make it easy Dumb-down (de-skill)	Increase choice Make it rich and subtle Create an environment for learning

Patients become designers

Meta-Designer

creates conditions in which

Designer

creates conditions in which

User

acts on

Artifact

learns from

learns from

responds to

Products

Tools

Languages (tools for making tools)

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"

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