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
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

↓

**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
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

- 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

**Means**  Medicines + therapies  Medicines + therapies

Self-management supported by HCPs, friends, and family

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

Millions of people reporting selected conditions 2003

- Pulmonary Conditions: 49.2
- Hypertension: 36.8
- Mental Disorders: 30.3
- Heart Disease: 19.2
- Diabetes: 13.7
- Cancers: 10.6
- Stroke: 2.4

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%
- 1 condition: 22%
- 2 conditions: 16%
- 3 conditions: 12%
- 4 conditions: 8%
- 5 or more conditions: 19%

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

Context
Social
- Activities
- Social interaction

Work
- Workload
- Work conditions

Geographic
- Location
- Environmental stressors

Medication Notes
SIDE EFFECTS
- Injection site pain/red/swelling
- Rash
- Shortness of Breath
- Joint pain
CONTRA-INDICATIONS
- Cold or Sinus Infections
Implications for design
A billion little experiments: each of us figuring out what’s working for us now

Observations compared to goals by... 
New observations suggest...

Person takes... 
Actions affect the...
...new actions

Body

Disturbances
trial and error ≈ experiment ≈
quality management ≈
≈ design
An enabling infrastructure: sensors+big data+services

Diagram showing the connections between sensors, observations, patient's PC, web-based applications, and dialogue with caregivers such as physician, nurse, health coach, family, and friends.
Industrial Age Medicine

- Primary
- Secondary
- Tertiary

Encouraged: More costly

Discouraged: Less costly

Source: Tom Ferguson, 1995

Self-care (off the map)
Information Age Health-care

Encouraged
- Individual self-care
- Family and friends
- Self-help networks

Discouraged
- Professionals as facilitators
- Professionals as partners
- Professionals as authorities

Source: Tom Ferguson, 1995
Recognizing a 4th distinct and legitimate health sphere

- Healthcare
- Self-care
- Medical Research
- Public Health
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.”

## Health frame eras summary

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

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

- Meta-Designer creates conditions in which Designer learns from User, who responds to Artifact.
- Designer creates conditions in which User learns from Artifact.
- User acts on Artifact, which generates Products.

Languages (tools for making tools)
Tools
Products
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”
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