Mayo Clinic Center for Innovation
Transform Conference
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Designing For Health & Well-being: Self-Tracking & Data Visualization

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A talk in five parts

1. Reframing health as more than healthcare—recognizing the importance of self-management
2. Four technology trends that support reframing
3. An introduction to control theory as background
4. Building tools to support self-management
5. A discussion with Ian Eslick

Part 1

Reframing Health

- Wicked problem
- A goal-means tree
- Asymmetric relations
- Era analysis

Most people agree that healthcare is a ‘wicked problem’.

Healthcare's many stakeholders can't agree on a solution, because they don't agree on the problem.

Wicked problems can only be resolved by reframing— by finding shared views, values, and goals.

From the point of view of **today's healthcare system**, health is largely about **minimizing illness**.

Traditional healthcare focuses on treating acute problems.

Goals Eliminate or minimize acute diseases and infirmities

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

Traditional health management applies the tools of acute care to stabilizing chronic conditions.

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

But health is more than eliminating or managing disease.

Goals	Health: Complete physical, mental, and social well-being*	
Means / Goals	Eliminate or minimize acute diseases and infirmities	Manage chronic conditions; avoid or slow deterioration leading to acute problems
Means	Medicine and other therapies administered by HCPs with patients' consent; patients have little say in means	Medicine and other therapies prescribed by physicians and administered by patients, who may have other priorities or may reject means

Health is a means to higher goals—‘a resource for everyday life’

Goals

Quality of everyday living

Means / Goals

Health:
Complete physical, mental, and social well-being*

Other goal/means, such as:
– Love of family + friends
– Work valued by self + others
– Physical and financial security
– Fun + joy

Means / Goals

Eliminate or minimize acute diseases and infirmities

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

Means

Medicine and other therapies administered by HCPs with patients’ consent; patients have little say in means

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

The requirements of health extend beyond traditional healthcare

Goals

Quality of everyday living

Means / Goals

Health:
Complete physical, mental, and social well-being*

Other goal/means, such as:
– Love of family + friends
– Work valued by self + others
– Physical and financial security
– Fun + joy

Means / Goals

Eliminate or minimize acute diseases and infirmities

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

Self-management supported by HCPs, family, friends, and peers

Other means, such as:
– Employer practices
– Social policies
– Providing essentials: clean air + water, food + shelter, education + stability

Means

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

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

People actively involved in their own:
– Monitoring...
– Goal-setting
– Experimenting...
– Understanding...
– Reflecting...

...in relation to their:
– Bodies
– Diet
– Activities
– Relationships
–Environment

The way we usually think about health today is bound up in the language of our healthcare system.

- Individuals are patients
- Doctors and nurses are professionals
- Professionals care for patients
- Patients receive treatment
- Not following a physician's orders means a patient is not in compliance

The language of acute care is ill-suited to managing chronic conditions or preventing disease (often framed as behavior change).

'The number 1 problem in treating illness today is patients' failure to take prescription medications.'

— American Heart Association

We *can* imagine a better world; we can invent a new language; we can create new systems; we can establish symmetric relationships

We can move

from **health** ⟶ to **well-being**

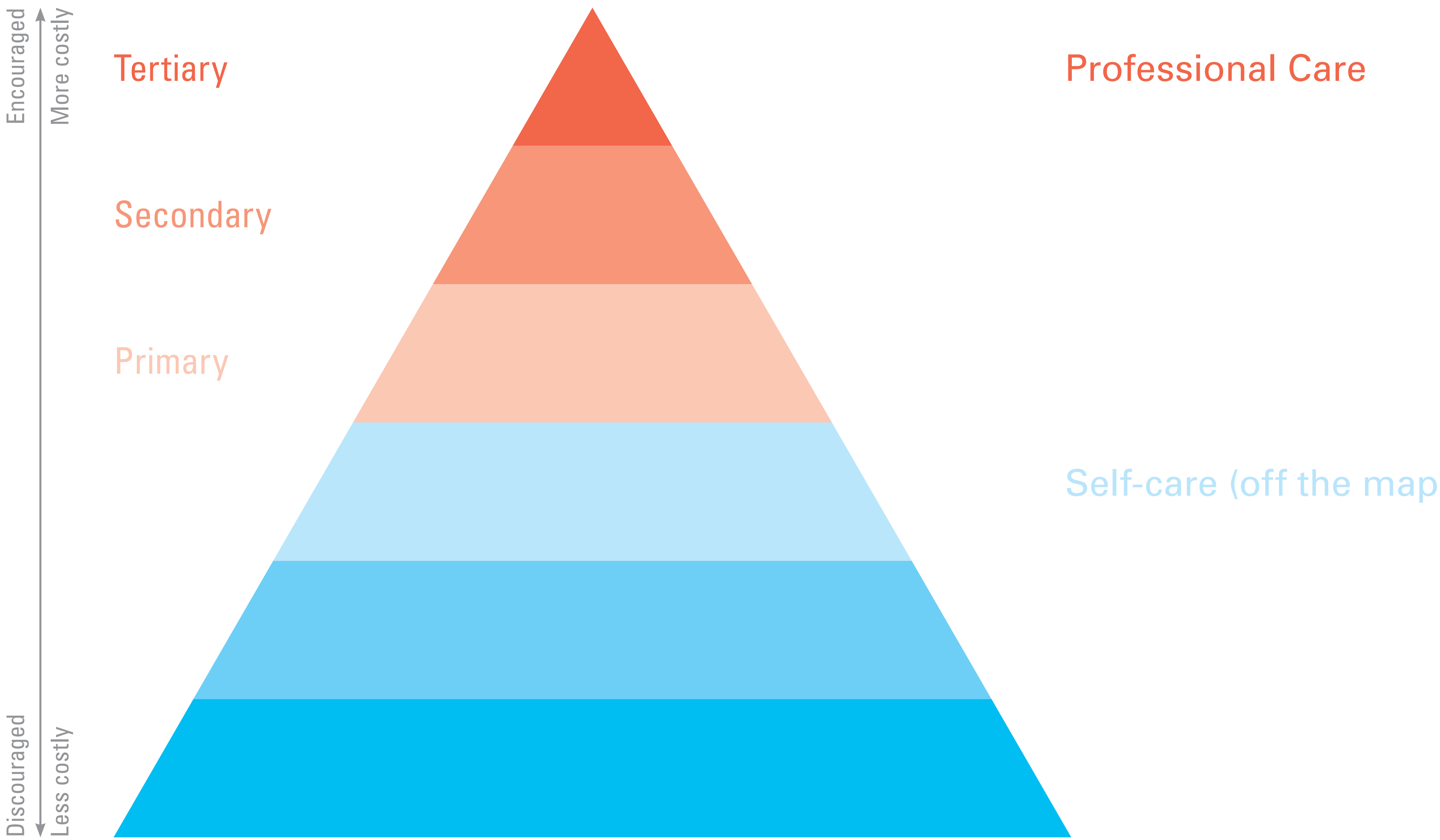
from **health-care** ⟶ to **self-management**

from **patient** ⟶ to **experiment designer**

'A collaborative co-care model
is starting to evolve for healthcare 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 collaborator.'

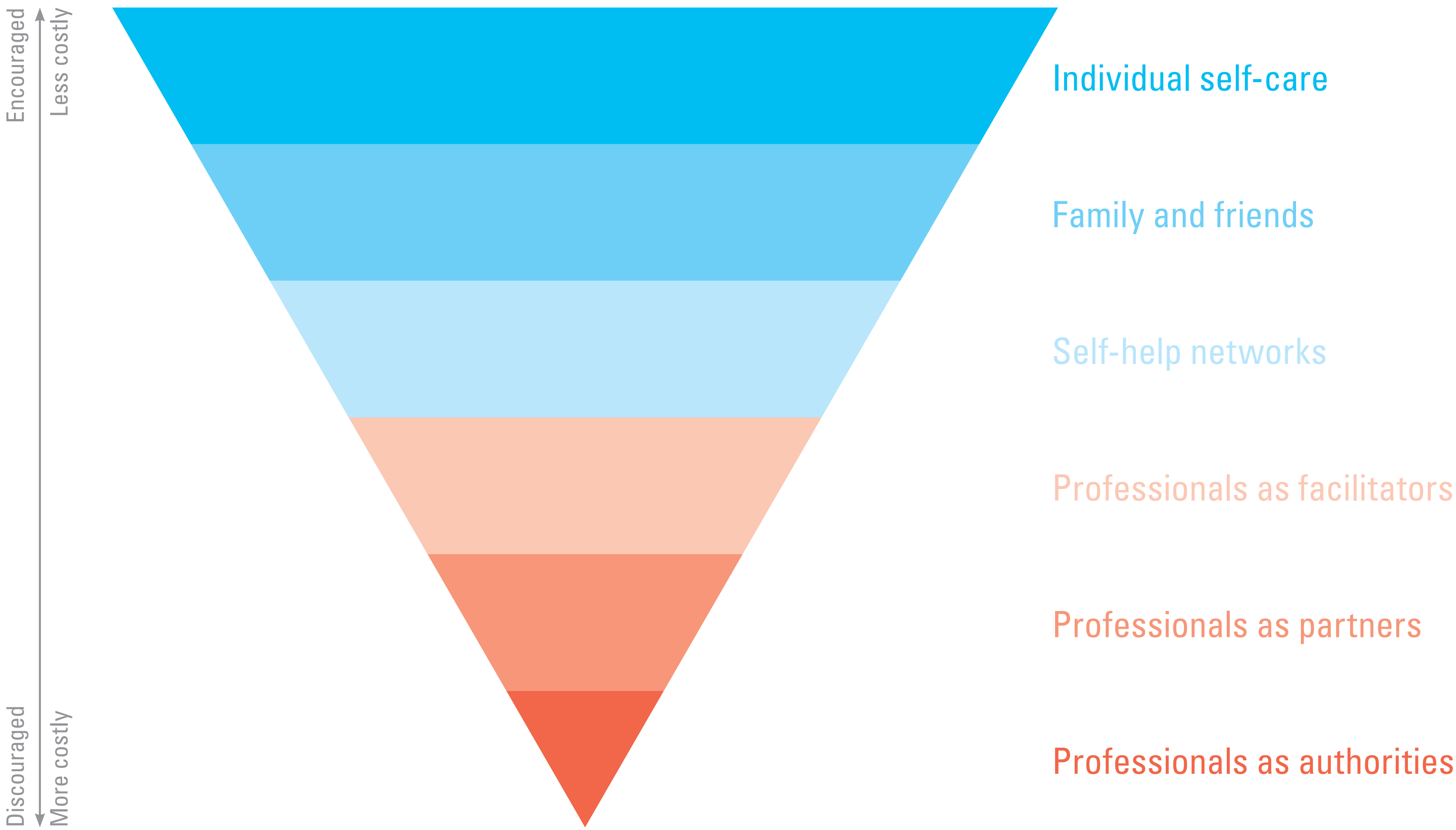
— Melanie Swan

Industrial-age health systems



— Tom Ferguson

Information-age health systems



— Tom Ferguson

Health eras summary

	Traditional Healthcare frame	Emerging Self-management frame
Scope	Relieve acute condition 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, & adjust; iterate Learn and adapt as you go
Subject	Symptoms and test results	Whole person, seen in context
Response	Prescribe medication	Improve behavior, environment
Relies on	Medical establishment	Individual, family, & friends Social networks, others like me

Health eras summary (cont.)

	Traditional Healthcare frame	Emerging Self-management frame
HCP as	Authority, expert Dispensing knowledge	Coach, assistant Learning from patients
Patient as	Helpless, childlike Taking orders	Responsible adult Setting goals; testing hunches
Relationship	Asymmetric, one-way Command and control	Symmetric, reciprocal Discussion and collaboration
Records	HCP's notes of visit Sporadic Dispersed between offices Managed by HCP	Patient's notes, data from sensors Continuously collected Connected; aggregated Controlled by patient

Reframing health as self-management parallels similar trends in design practice; increasingly we recognize that users manage (or design) their own experiences.

Design 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) Completed	Increase choice Make it rich and subtle Create an environment for learning Open-ended

Part 2

Technology Trends

– Sensors
– Big data
– Convergence 2.0
– Self-tracking

Part 2.1

Technology Trends

Sensors are proliferating and connecting

They will be ubiquitous

- **at check points**
- **on line**
- **all around**
- **on you**
- **in you**

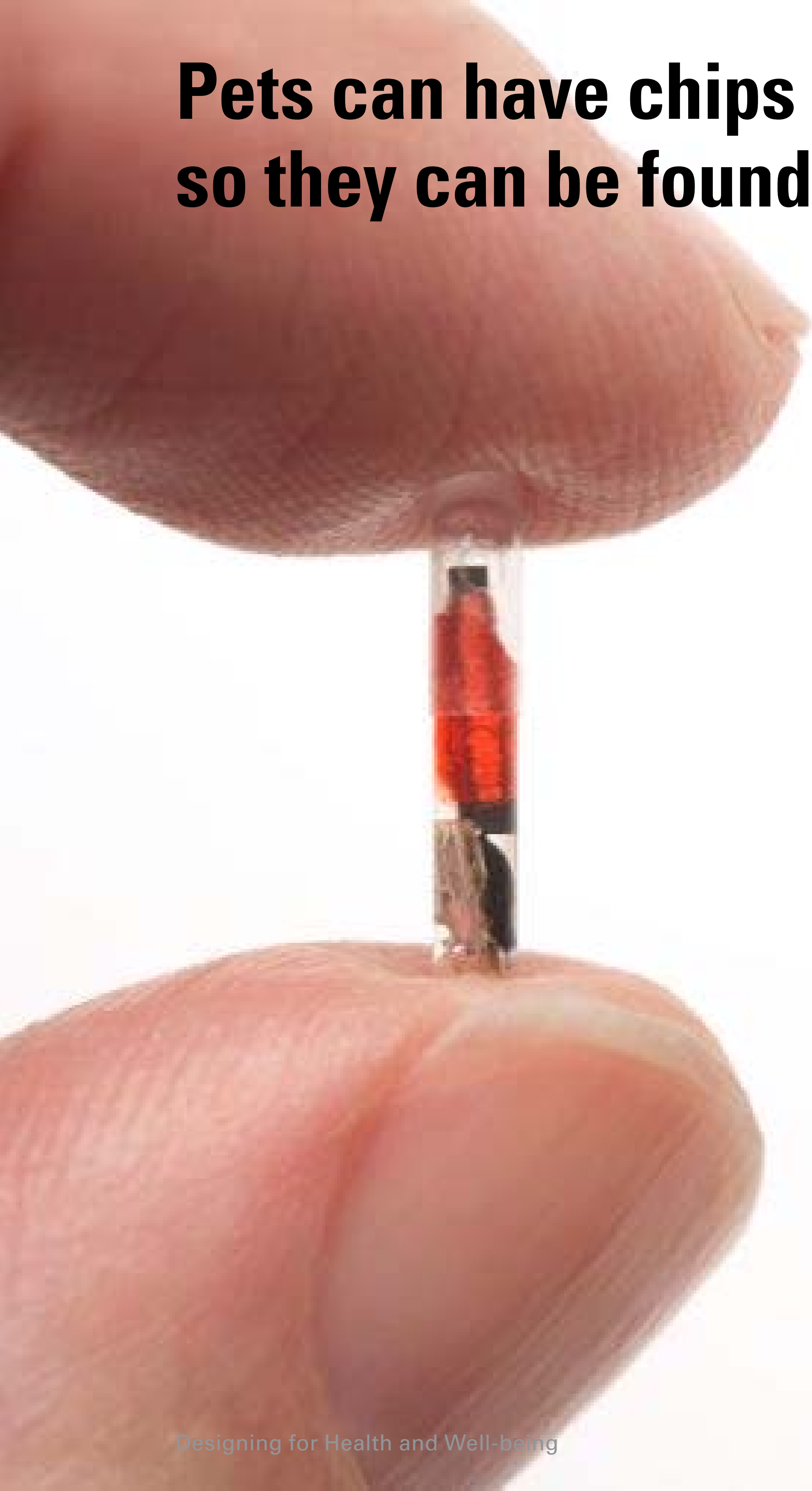
Wal-Mart has mandated that every package in its stores include an RFID chip.

London alone already has 500,000 video surveillance cameras.

Chicago has about 15,000 cameras, networked so that a 911 call automatically displays images from the nearest camera.

Intel has chips measuring heat and humidity on each vine in several California vineyards.

Pets can have chips implanted so they can be found more easily.



Mobile phones are packed with sensors and becoming hubs for body-area networks

– Motion (accelerometer)
– Compass (magnetometer)
– Location (GPS)
– Sound (microphone)
– Light (camera × 2)
– Touch
– Proximity (to face)

Part 2.2

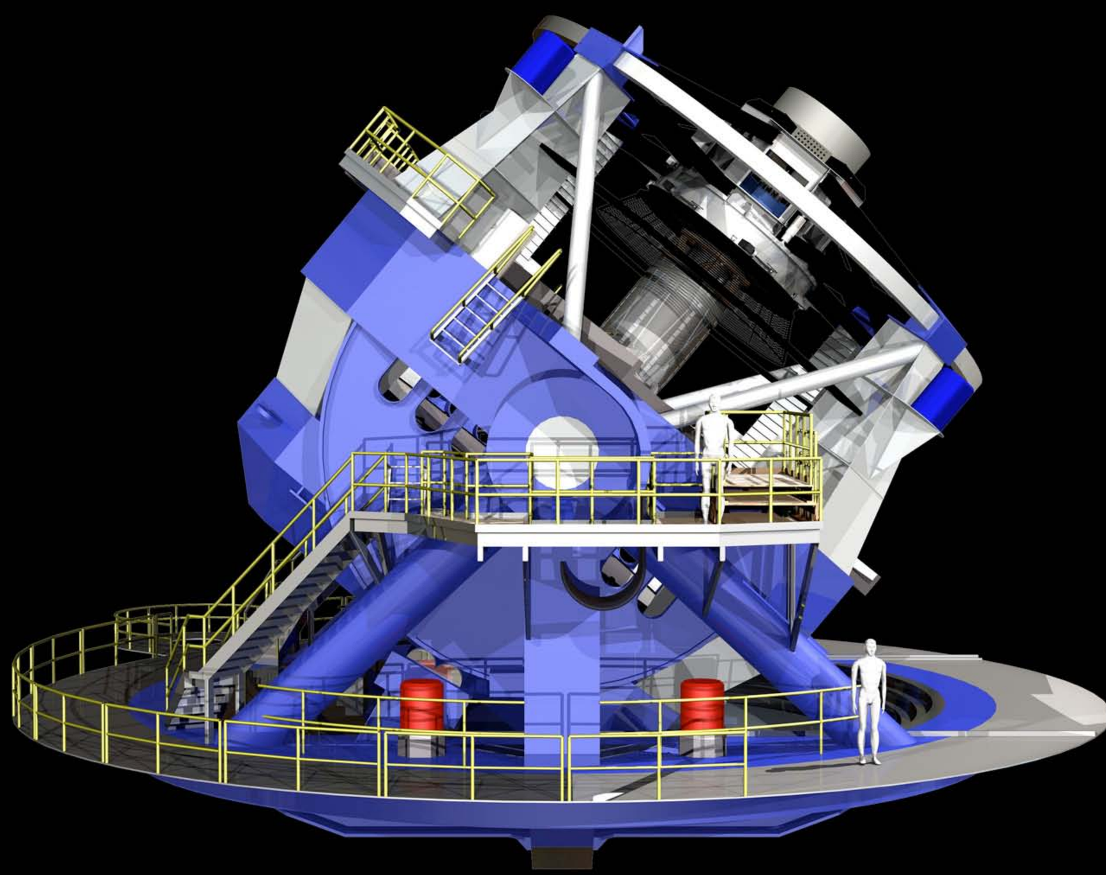
Technology Trends

Big Data: assembling, managing, & mining huge databases

– Logging every user action
– Measuring every design change
– Relying on statistics

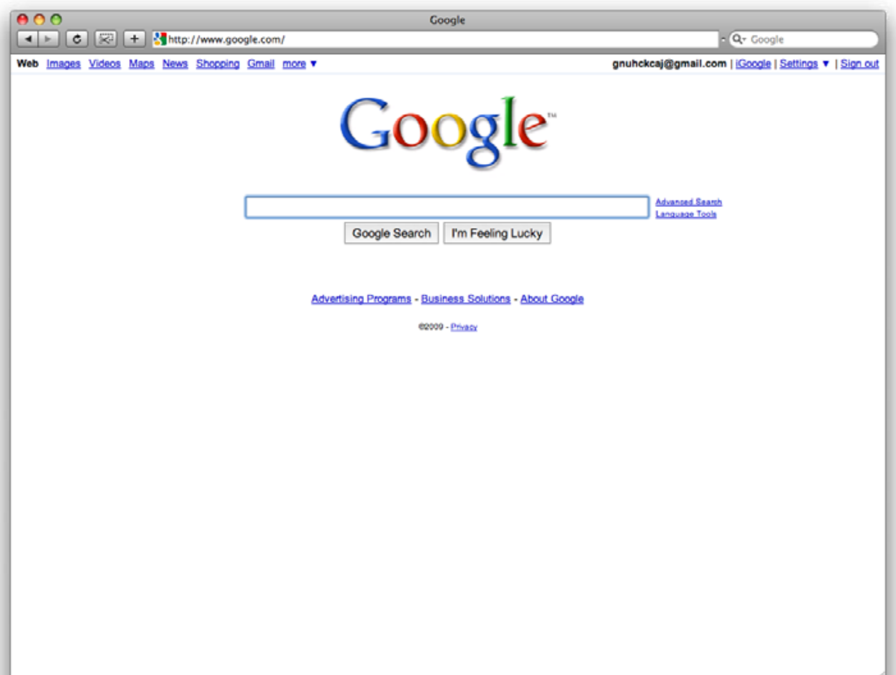
The new Large Synoptic Survey Telescope (LSST) will produce 30 terabytes of data each night.

The current largest public database of such images is about 80 terabytes.

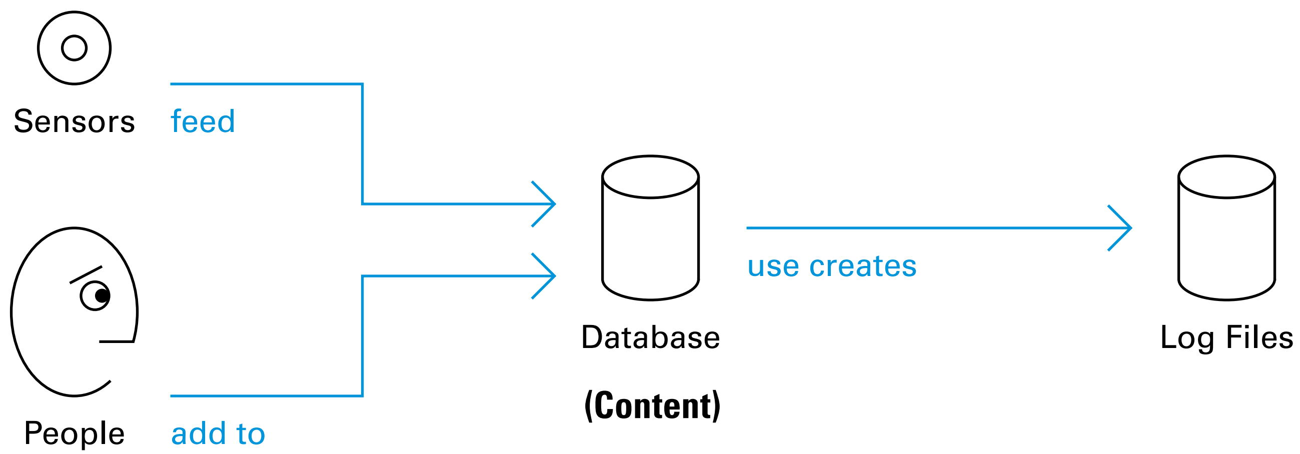


Google + Amazon have built big businesses collecting huge amounts of data.

They are not anomalies,
they are signals of the future.

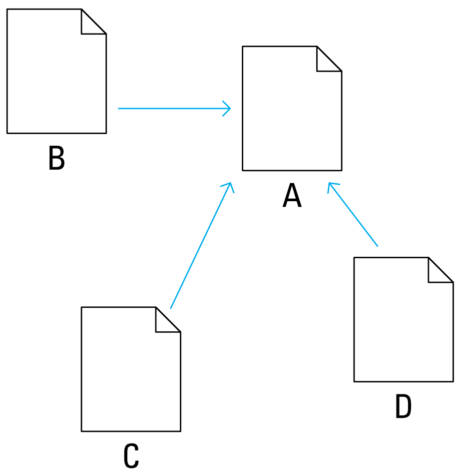


Big data collection has 3 levels.



Large data collections are inherently valuable.

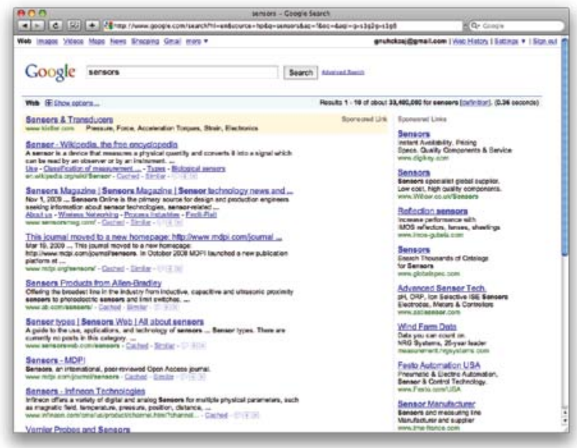
Links on the web



Page rank index

A	⟵	B, C, D
B		
C		
D		

Google search results



The result?
Analytics for everything, everyone, and you.

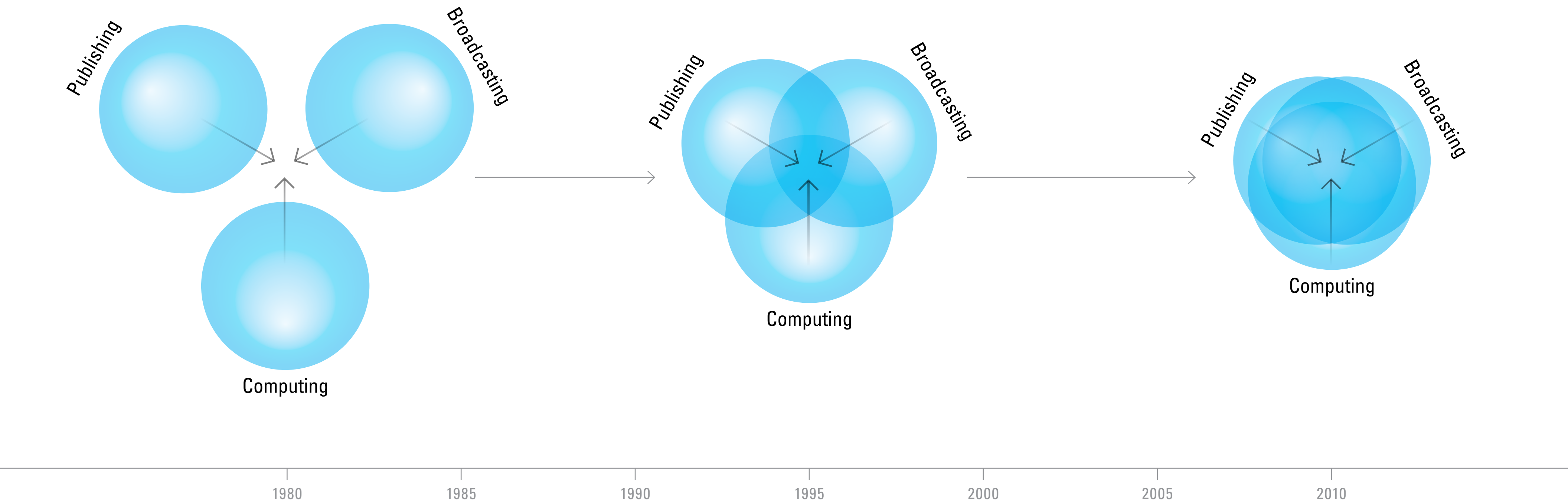
Part 2.3

Technology Trends

A larger trend is at work: Convergence

– All media becoming digital
– Networks becoming services
– Healthcare becoming digital & networked
– The rise of personal archives

Convergence 1.0:
Publishing + broadcasting + computing



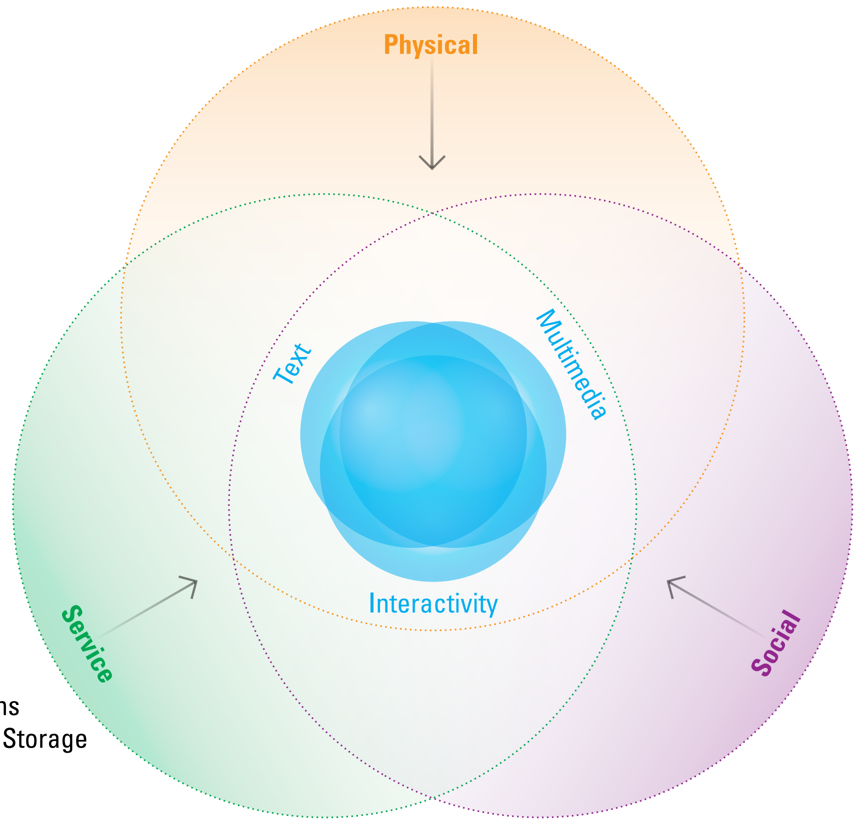
Books, applications, and rich media are distinct entities, but moving toward each other.

Convergence of books, applications, and rich media.

Books are evolving to become multi-media, interactive, social, and service oriented. These are all aspects of the converging technology of books.

Convergence 2.0:
Service + social + physical

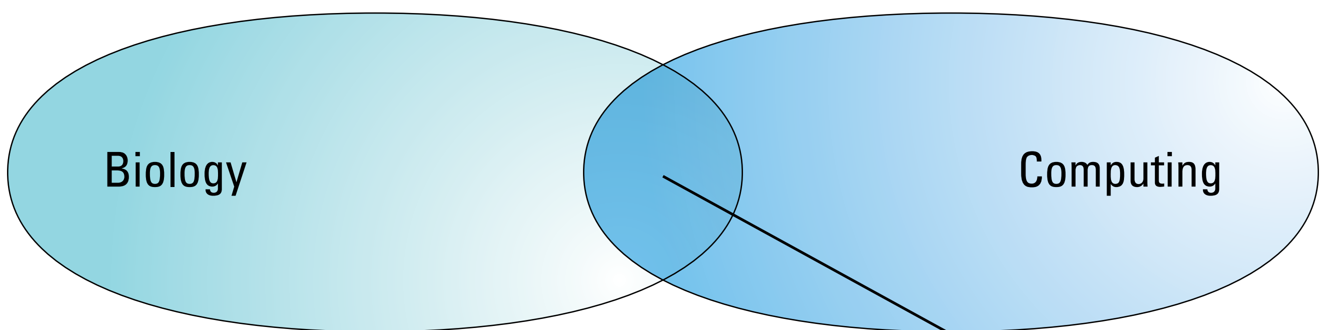
Location (GPS)
Sensors
Internet of Things
GEO-Spatial Web



Routing + DNS
Communications
Computation + Storage
Search
Maps
Media Access
Payment + Advertising
Speech + Image Recognition
Automated Translation

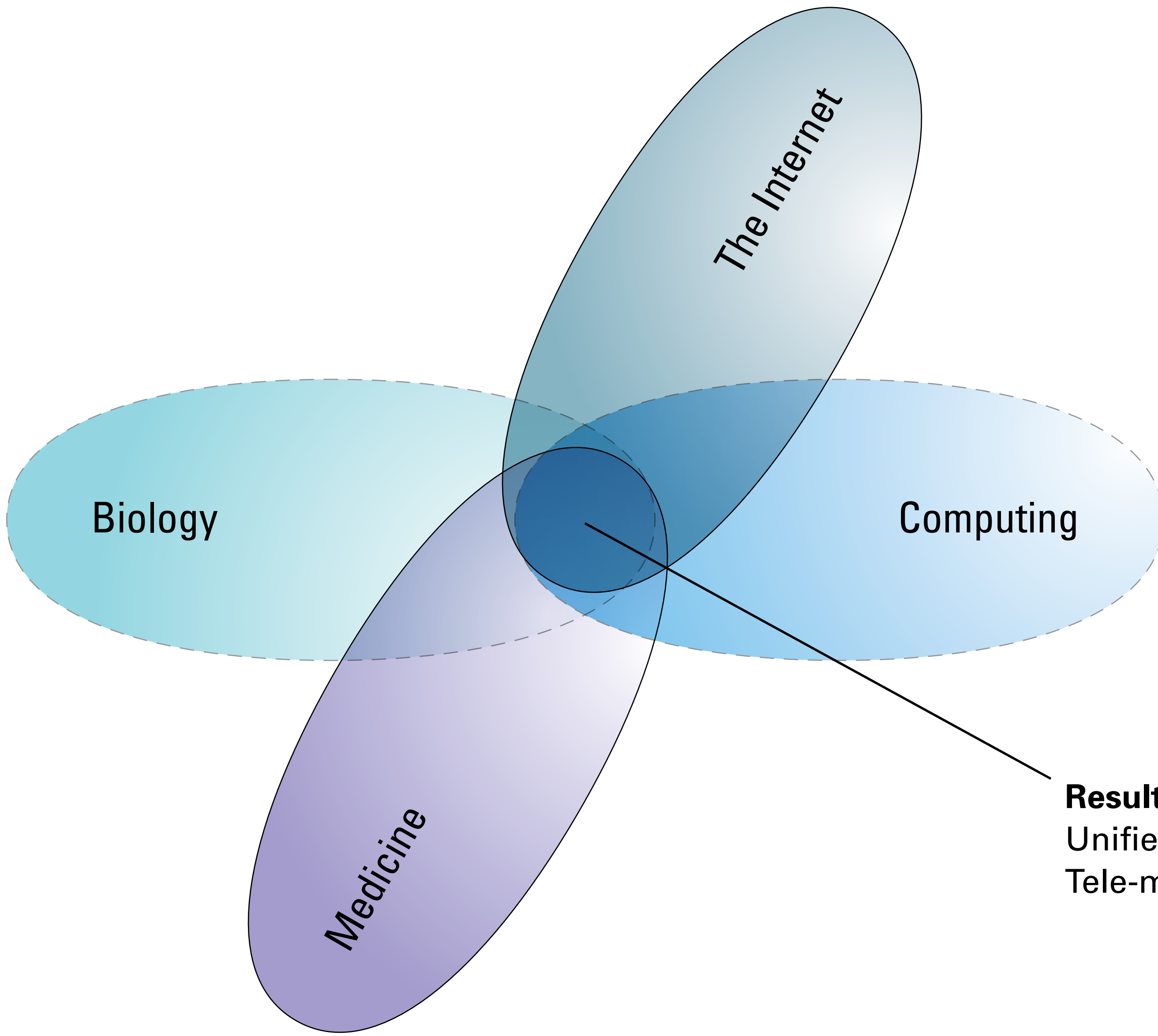
ID + Authentication
Contacts
Social Graph
Conversations
Calendar + Time
UGC + Crowd-sourcing
Activity Streams
Government Data

Convergence is even larger.
Biology is becoming a computational science.



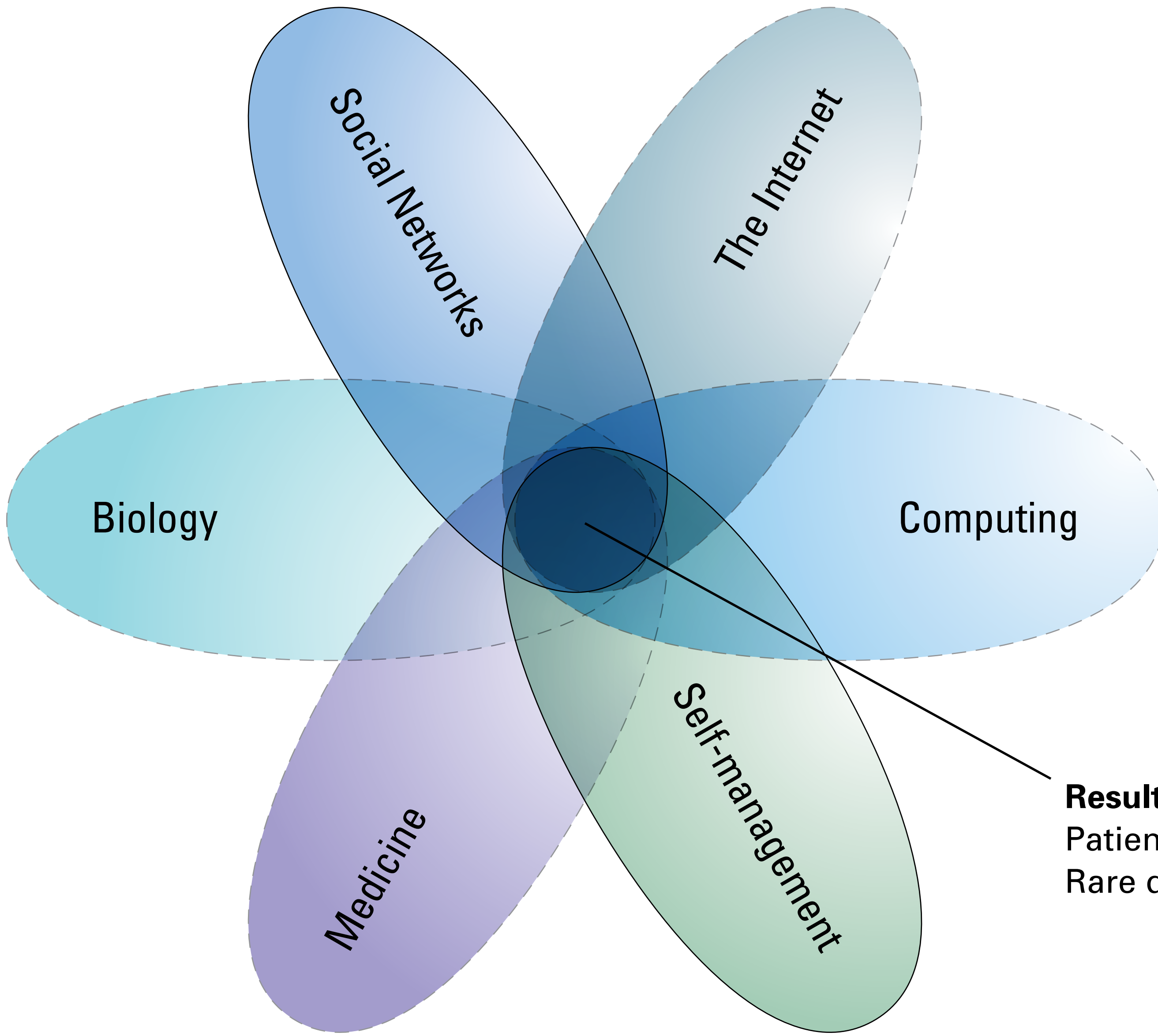
Results include
Genomics
Proteomics

The internet is beginning to transform the practice of medicine.



Results include
Unified EMR/PHR
Tele-medicine

Social networks will merge with dashboards to enable self-management.



Results include
PatientsLikeMe.com
Rare disease networks

Convergence will hasten the growth of personal archives—and their integration.

		Health Wellness Physical Data	**Finance** Assets Transactions	**Education** Experience Media Consumed	**Social** Contacts Calendar Communications Travel
Future	*Goals* – *Opportunities* – *Threats*			Amazon Wishlist	
Present	*Status* – *Strengths* – *Weaknesses*		Mint Online Wallets		Facebook Single Sign-on
Past	*Records* – *Successes* – *Failures*	EMR / PHR		Evernote Amazon Purchase History	

Part 2.4

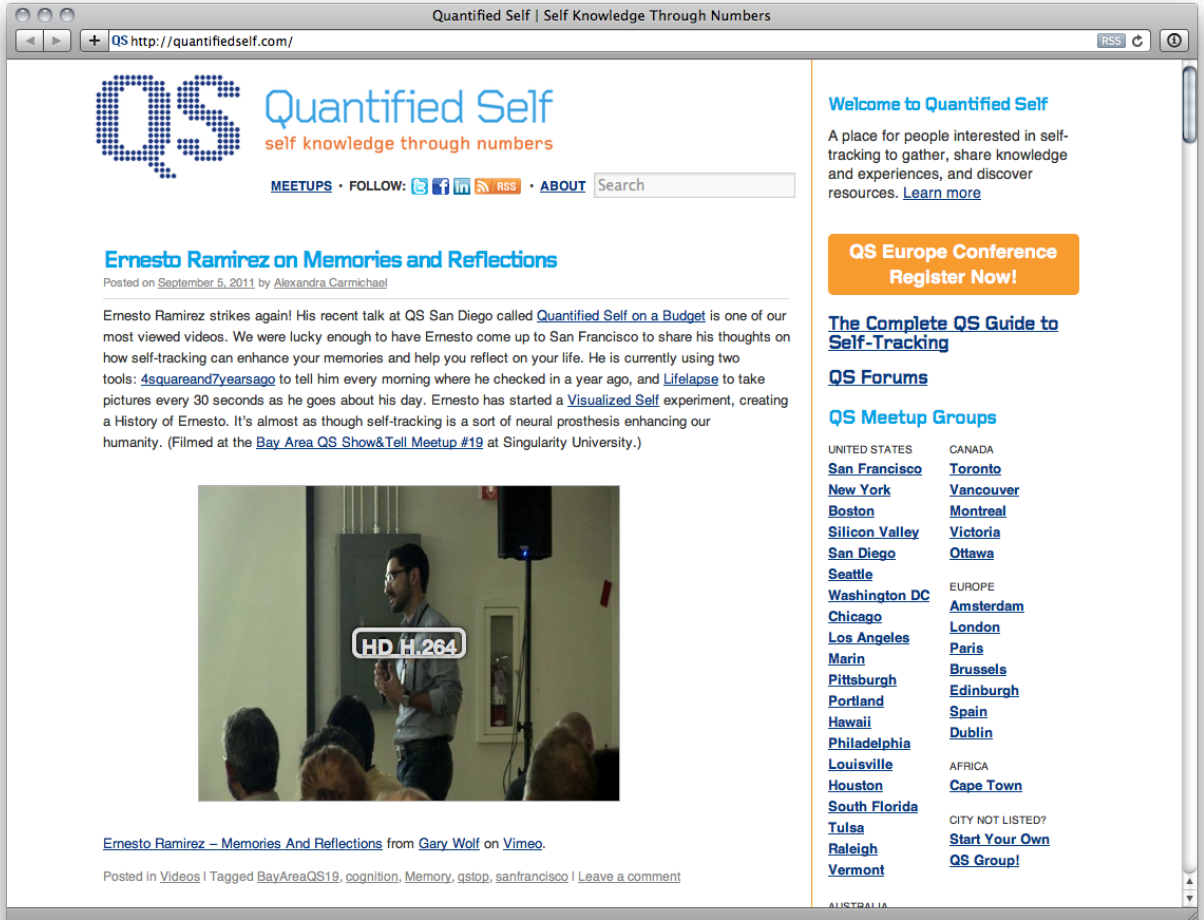
Technology Trends

Self-tracking

'... anyone who makes note of their blood pressure, weight, or menstrual cycle could be categorized as a "self tracker".'
— Carol Torgan

Quantified Self Group (QS)

- Gary Wolf
- Rajiv Mehta
- Steven Dean



27% of adult internet users track health data online.

‘Our survey finds that 15% of internet users have tracked their weight, diet, or exercise routine online. In addition, 17% of internet users have tracked any other health indicators or symptoms online. Fully 27% of adult internet users say yes to either question.’

— ’The Social Life of Health Information’, Pew Research Center

‘Wireless users are more likely than other internet user to track health data online.’

‘Separately, looking at just the 85% of adults who own a cell phone, 9% say they have software applications or “apps” on their phones that help them track of manage their health.’

Apple's App Store offers more than 1885 diet tracking apps for iPhone and another 475 for iPad.

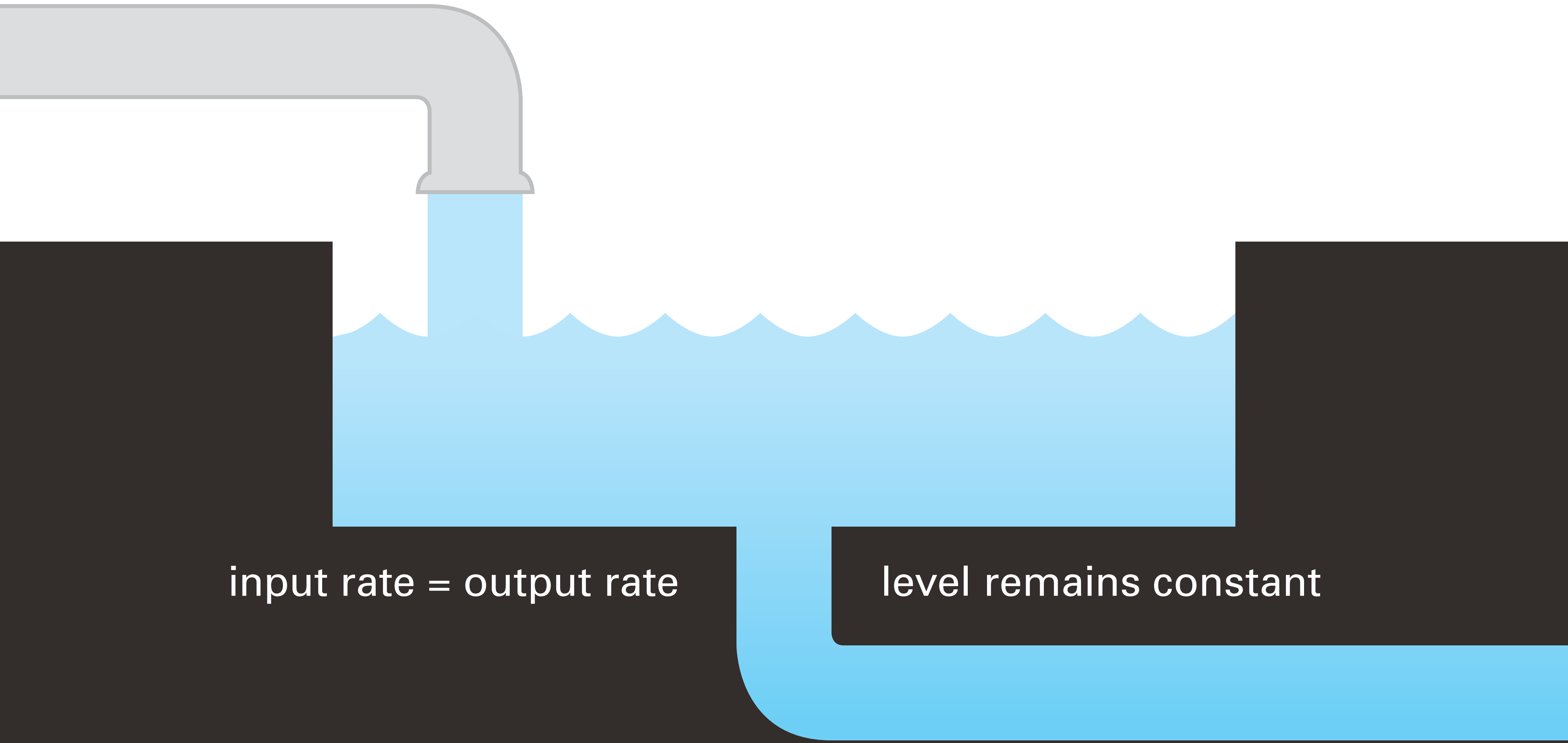
Part 3

Control Theory

– Dynamic equilibrium
– Feedback
– Improving improvement

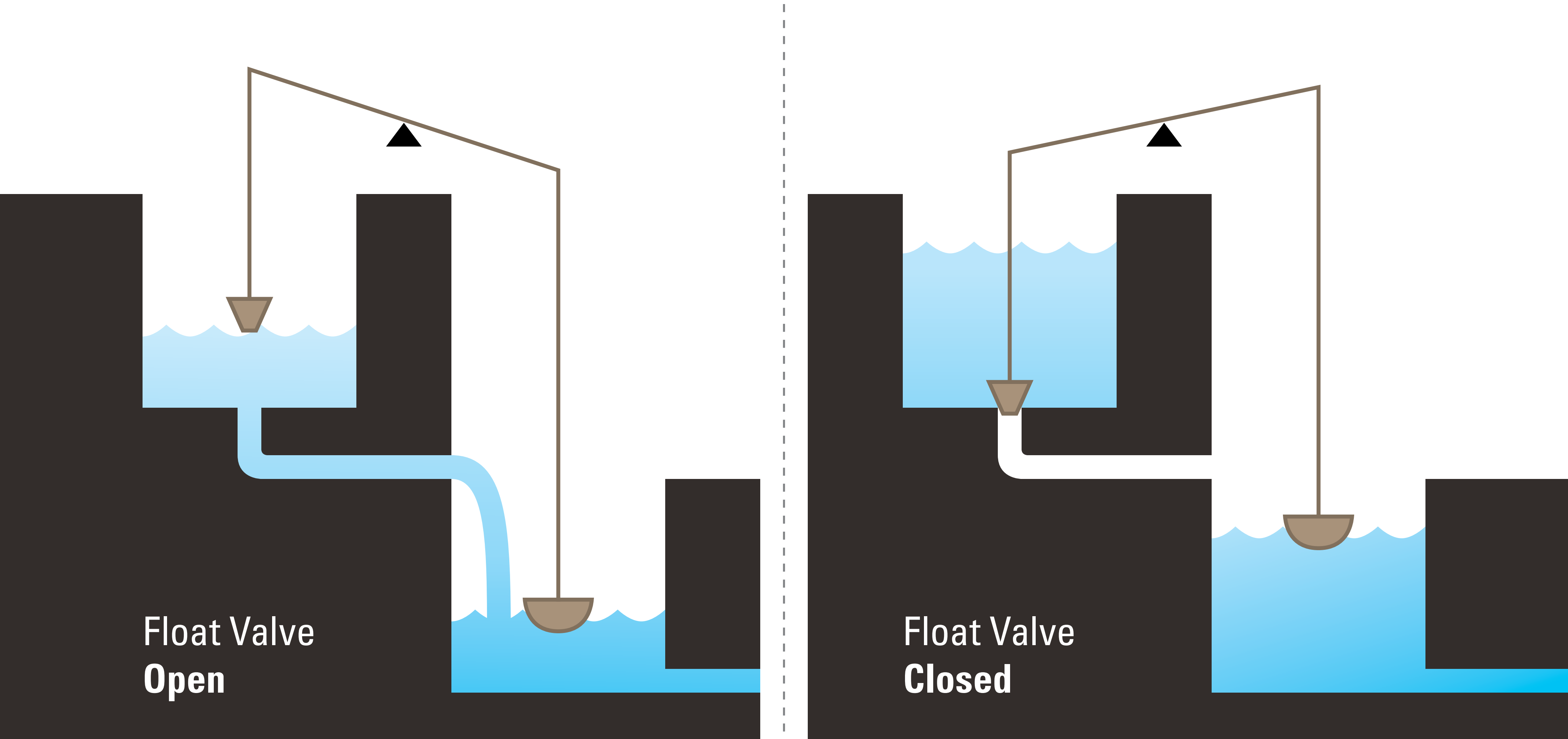
Dynamic equilibrium

In a reservoir, the rate of water flowing in = the rate of water flowing out;
keeping the reservoir within bounds —
not letting it run dry and not letting it overflow.



Dynamic equilibrium is maintained by feedback

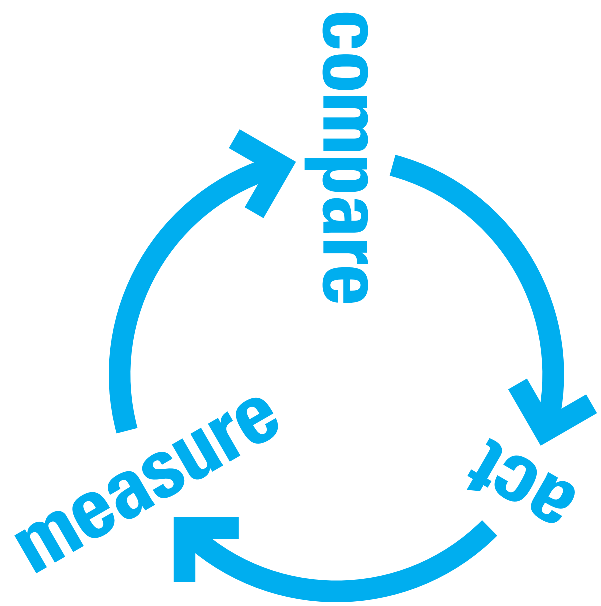
Measuring the effect of an action, comparing it with a goal
(maintaining the level of water in the reservoir)
and acting to correct differences



This feedback loop is a structure common to all control mechanisms: act, measure, compare to goal, act-to-correct differences

self-regulating system

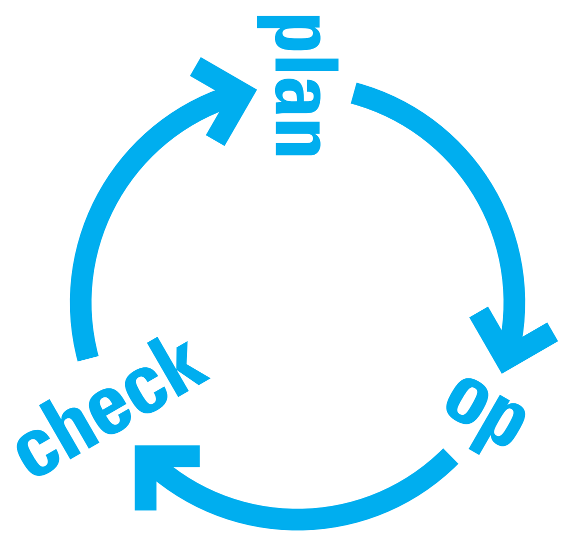
Like a self-regulating system, the creative process is a classic feedback loop. Measure an essential variable; compare it to a goal; and act to eliminate any difference.



This process is similar to the Shewart-Demming PDCA (plan-do-check-act) process.

quality cycle

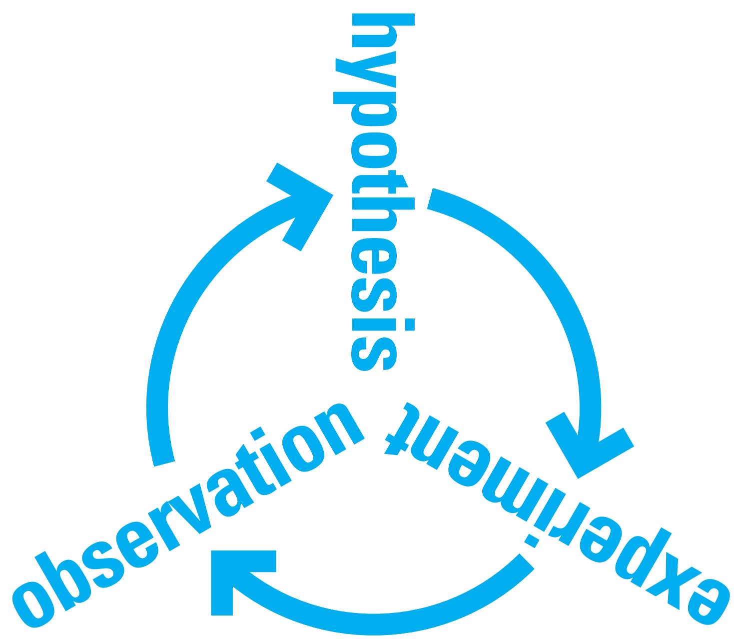
The creative process is startlingly similar to the quality cycle (Shewart, 1939), popularized in business circles by the quality management movement (Deming, 1982).



It’s also an analog to the design process and the scientific method.

scientific method

Forming a hypothesis is a special type of creative act. Framing the creative process as “experimenting” shows the close tie it has with the domain of science.



Tracking by itself is only useful if you can make correlations.

Tracking measuring + recording, perhaps correlating measurements
Open loop system, no feedback

Tracking + acting = managing

Managing measuring, comparing to goal, + acting to correct differences
Closed loop system, feedback enables dynamic equilibrium (homeostasis)
—first order

Tracking measuring + recording, perhaps correlating measurements
Open loop system, no feedback

Managing may lead to learning

Learning anticipating disturbances + affects of actions
Studying the system, developing a model of the feedback loop
—second order

Managing measuring, comparing to goal, + acting to correct differences
Closed loop system, feedback enables dynamic equilibrium (homeostasis)
—first order

Tracking measuring + recording, perhaps correlating measurements
Open loop system, no feedback

Learning may lead to experimenting

Innovating recognizing patterns, proposing causes, + testing hypotheses
Studying the environment, experimenting to see how the system connects to other systems

Learning anticipating disturbances + affects of actions
Studying the system, developing a model of the feedback loop —second order

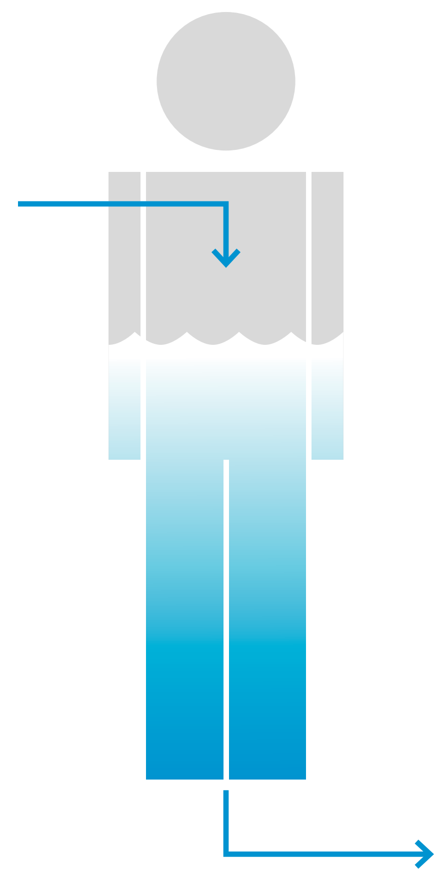
Managing measuring, comparing to goal, + acting to correct differences
Closed loop system, feedback enables dynamic equilibrium (homeostasis) —first order

Tracking measuring + recording, perhaps correlating measurements
Open loop system, no feedback

Part 4

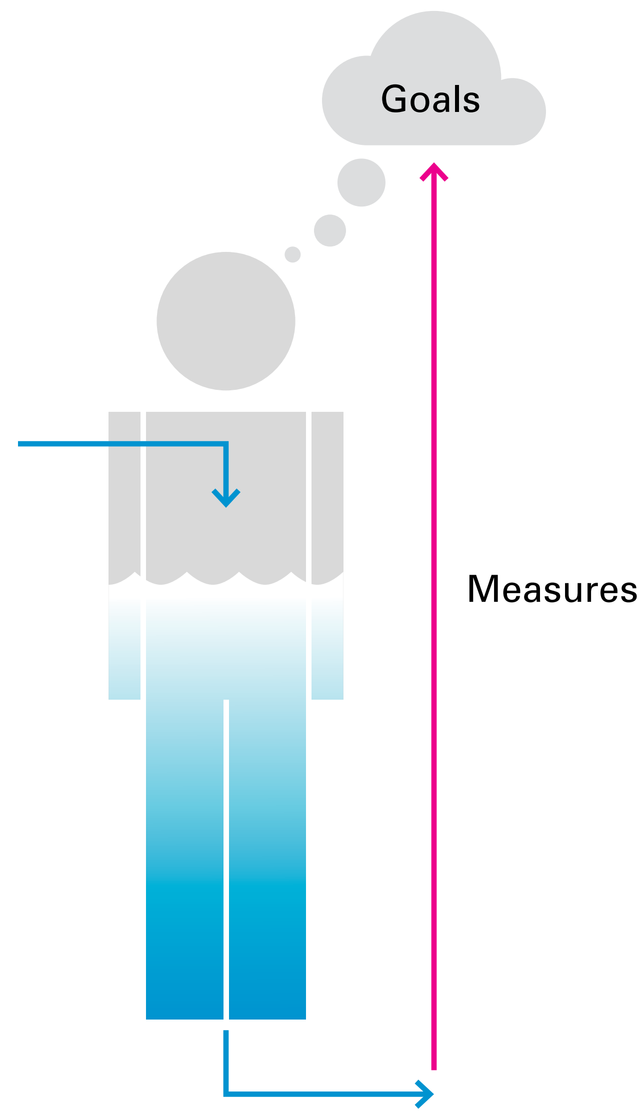
Building Tools

Living systems must maintain dynamic equilibrium (homeostasis) to survive

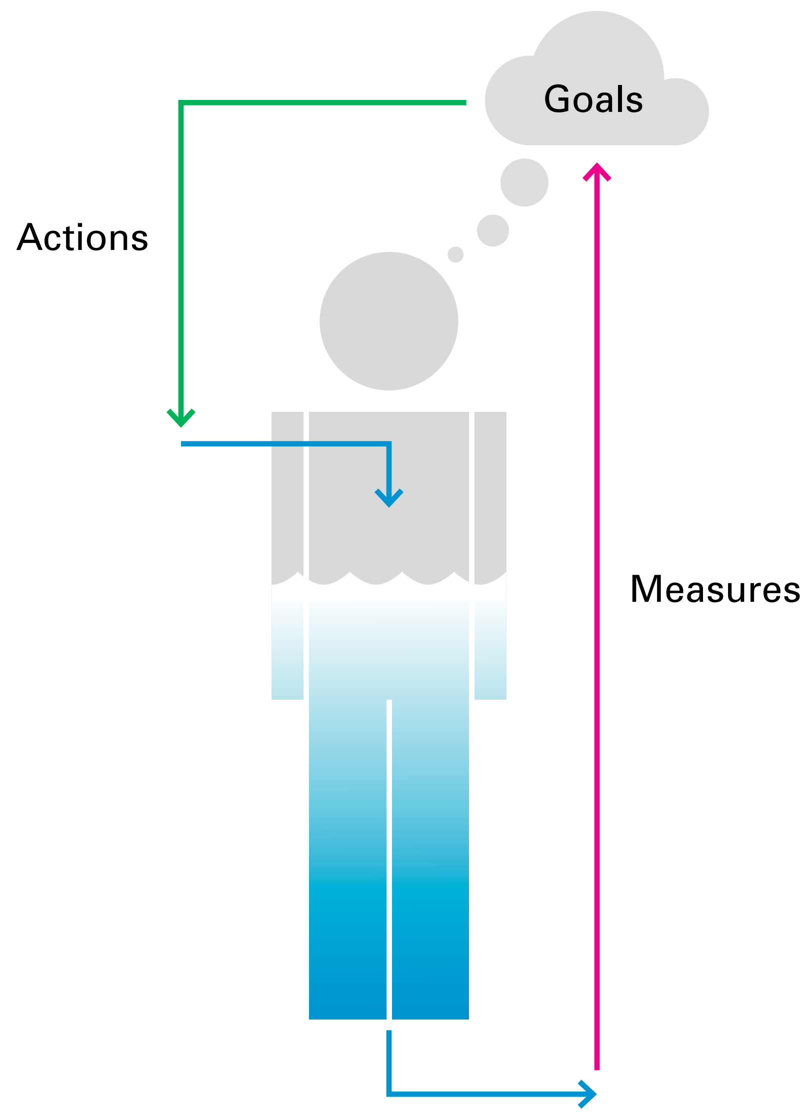


A patient's vital signs measure important elements of homeostasis

Variable	Goal range
Body temperature	97.25°F – 99.5°F
Heart rate	60 – 80 bpm
Blood pressure	< 120 / < 80 mm Hg
Respiratory rate	10 – 14 bpm



Maintaining homeostasis requires ‘closing the loop’ on many variables simultaneously



Common lab tests measure other elements of homeostasis and may indicate therapies

Variable	Goal range	Therapy
Weight	150 – 170 lbs	Diet, exercise
BG (fasting)	70 – 99 mg/dL	Diet, insulin
INR	0.8 – 1.2	Diet, warfarin
Cholesterol	< 200 mg/dL	Diet, statins

A quick survey turned up more than 150 analytes that can be measured in lab tests today.

Pulse regularity
Respiratory rate
Bone density
Cross-linked N-telopeptides
Vitamin D
Uric acid
Blood vessel dilation
Muscle mass
Sodium
Potassium
Calcium
Magnesium
Chloride
Hydrogen phosphate
Hydrogen carbonate
Total serum iron
Total iron-binding capacity
Transferrin
Transferrin saturation
Ferritin
Ammonia
Copper
Zinc
Magnesium
Selenium
Ceruloplasmin
Blood vessel supply
Dopaminergic neuron quantity
Glucose
Protein
Red blood cells
White blood cells
Blood pressure
Refractive error
Pressure
Clarity
Hearing sensitivity
Thyroid stimulating hormone
Free thyroxine
Free triiodothyronine
Total thyroxine

Body mass index
Epinephrine
Cortisol
17 hydroxyprogesterone
Angiotensin-converting enzyme
Growth hormone
Follicle-stimulating hormone
Luteinizing hormone
Adrenocorticotropic hormone (ACTH)
Prolactin
Pulse
Pressure
Blood Glucose
Insulin absorption
Plasma osmolality
Total cholesterol
High density lipoprotein (HDL)
Low density lipoprotein (LDL)
Triglycerides
pH
H+
Base excess
Oxygen pressure
Oxygen saturation
Carbon dioxide
Standard bicarbonate
Hemoglobin
Hemoglobin in plasma
Glycosylated hemoglobin
Haptoglobin
Hematocrit
Mean cell volume
Red blood cell distribution width
Mean corpuscular hemoglobin concentration
Erythrocytes/Red blood cells
Reticulocytes
Thrombocyte / platelet count
Prothrombin time
Coagulate production

Bleeding time
Viscosity
D-dimer
Creatine kinase
CPK-MB
Brain natriuretic peptide
NT-proBNP
Myoglobin
Troponin–I
Troponin–T
Lung volume
Oxygen absorption
Hypopneas
Neutrophil granulocytes
Neutrophilic band forms
Lymphocytes
Monocytes
Mononuclear leukocytes
CD4+ cells
Eosinophil granulocytes
Basophil granulocytes
Erythrocyte sedimentation rate
C-reactive protein
Alpha 1-antitrypsin
Immunoglobulin A
Immunoglobulin D
Immunoglobulin E
Immunoglobulin G
Immunoglobulin M
Anti-SS-A (Ro)
Anti-SS-B (La)
Anti ds-DNA
Anti-histone antibodies
Cytoplasmic/classical anti-neutrophil cytoplasmic antibodies
Perinuclear anti-neutrophil cytoplasmic antibodies
Anti-mitochondrial Antibodies
Rheumatoid factor
Antistreptolysin O titre

Albumin
Globulin
Total Bilirubin
Direct/conjugated bilirubin
Lipase
Plaque regulation
Amylase
H.pylori
Lumen obstruction
Gastrin
Fecal occult blood
Serum creatinine
Urine specific gravity
Osmolality
Uribilinogen
RBC casts
Ketone bodies
Nitrite
NMP22 protein
Sperm
Testosterone
Dihydrotestosterone
Estradiol
Progesterone
Prostate specific antigen
Human chorionic gonadotropin
Alpha-fetoprotein
Human chorionic gonadotropin
CA19-9
CA-125
Carcinoembryonic antigen
Homocysteine
Herpes simplex 1&2
Hepatitis A
Hepatitis B
Hepatitis C
Cytomegalovirus
HIV
Inluenza
Measles
Human papillomavirus

We are organizing these markers into a taxonomy

We are building a database that describes how the individual variables within the larger system are related to and affect one another

		enzyme (ACE)
		Cortisol (hydrocortisone)
	Pituitary gland	Prolactin
		Follicle-stimulating hormone (FSH)
		Luteinizing hormone (LH)
		Adrenocorticotropic hormone (ACTH)
Cardiovascular	Blood	Blood pressure
		Blood glucose
		Insulin absorption
		Plasma osmolality
	Blood: lipids	Total cholesterol (TC)
		HDL
		LDL
		Triglycerides
		TC/HDL ratio
	Blood: acid, base & blood gases	pH
		H+
		Base excess
		Carbon dioxide
		Oxygen pressure
		Oxygen saturation
		Standard bicarbonate (SBC_e)
	Blood: hematology (red blood cells)	Hemoglobin (Hb)

. . . a database of reference ranges for key markers . . .

System	Component	Variable	Range	Measurement method	Potential disorder
Cardiovascular	Blood: lipids	Total cholesterol * in mg/dL	Desirable: < 200 Borderline high: 200–239 High: > 240	Blood	Hyper/hypo-choleste olemia, coronary hea disease, heart failure
		High density lipoprotein (HDL) * in mg/dL	Poor: < 40 (men) < 50 (women) Better: 50–59 Best: > 60	Blood	Atherosclerosis
		Low density lipoprotein (LDL) * in mg/dL	Ideal: < 100 Near ideal: 100–129 Borderline high: 130–159 High: 160–189 Very high: > 190	Blood	Atherosclerosis
		Triglycerides	mal, low risk: 150 mg/dL rline high: 0–199 mg/dL : 00–499 mg/dL ery high: > 500 mg/dL	Blood	Arther s, hea diseas
	Blood: acid, base & blood gases	pH	Arterial, normal: 7.34–7.44	Blood	Metabolic acidosis, respiratory acidosis

System is composed of Component; Component may have many Variable; Variable are measured in Range; Range via Measurement method.

Body systems

Markers

Disorders

. . . which link markers to disorders . . .

omponent	Variable	Range	Measurement method	Potential disorder	Therapies	# Affec
ood: lipids	Total cholesterol * in mg/dL	Desirable: < 200 Borderline high: 200–239 High: > 240	Blood	Hyper/hypo-cholester-olemia, coronary heart disease, heart failure	Diet, medications, alternative medicine, surgery (heart disease)	Hyperc 110 Corona 17.6 Heart f 5.8 r
	High density lipoprotein (HDL) * in mg/dL	Poor: < 40 (men) < 50 (women) Better: 50–59 Best: > 60	Blood	Atherosclerosis	Diet, exercise, weight loss, smoking cessation, fibrates, niacin	4.6 mil
	Low density lipoprotein (LDL) * in mg/dL	Ideal: < 100 Near ideal: 100–129 Borderline high: 130–159 High: 160–189 Very high: > 190	Blood	Atherosclerosis	Statins, ezetimibe, niacin, clofibrate, tocotrienols, diet	4.6 mil
	Triglycerides	mal, low risk: 150 mg/dL erline high: 0–199 mg/dL : 00–499 mg/dL ery high: > 500 mg/dL	Blood	Arther s, heart diseas	Diet, exercise, supplements (fish oil, flax seed oil), Carnitine	-
ood: acid, base & blood gases	pH	Arterial, normal: 7.34–7.44	Blood	Metabolic acidosis, respiratory acidosis	-	-

can lead to

Markers

Disorders

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. . . and disorders to therapies and effects

asurement method	Potential disorder	Therapies	# Affected	Cost of treatment	Alere tests for this with
od	Hyper/hypo-cholester-olemia, coronary heart disease, heart failure	Diet, medications, alternative medicine, surgery (heart disease)	Hypercholesterolemia: 110 million Coronary heart disease: 17.6 million Heart failure: 5.8 million	$100 –	Cholesterol LDX
od	Atherosclerosis	Diet, exercise, weight loss, smoking cessation, fibrates, niacin	4.6 million (USA)	$259 billion (USA)	Cholesterol LDX
od	Atherosclerosis	Statins, ezetimibe, niacin, clofibrate, tocotrienols, diet	4.6 million (USA)	$259 billion (USA)	Cholesterol LDX
od	Arther s, heart diseas	Diet, exercise, supplements (fish oil, flax seed oil), Carnitine	-		Cho
od	Metabolic acidosis, respiratory acidosis	-	-	-	Epocal

is associated with

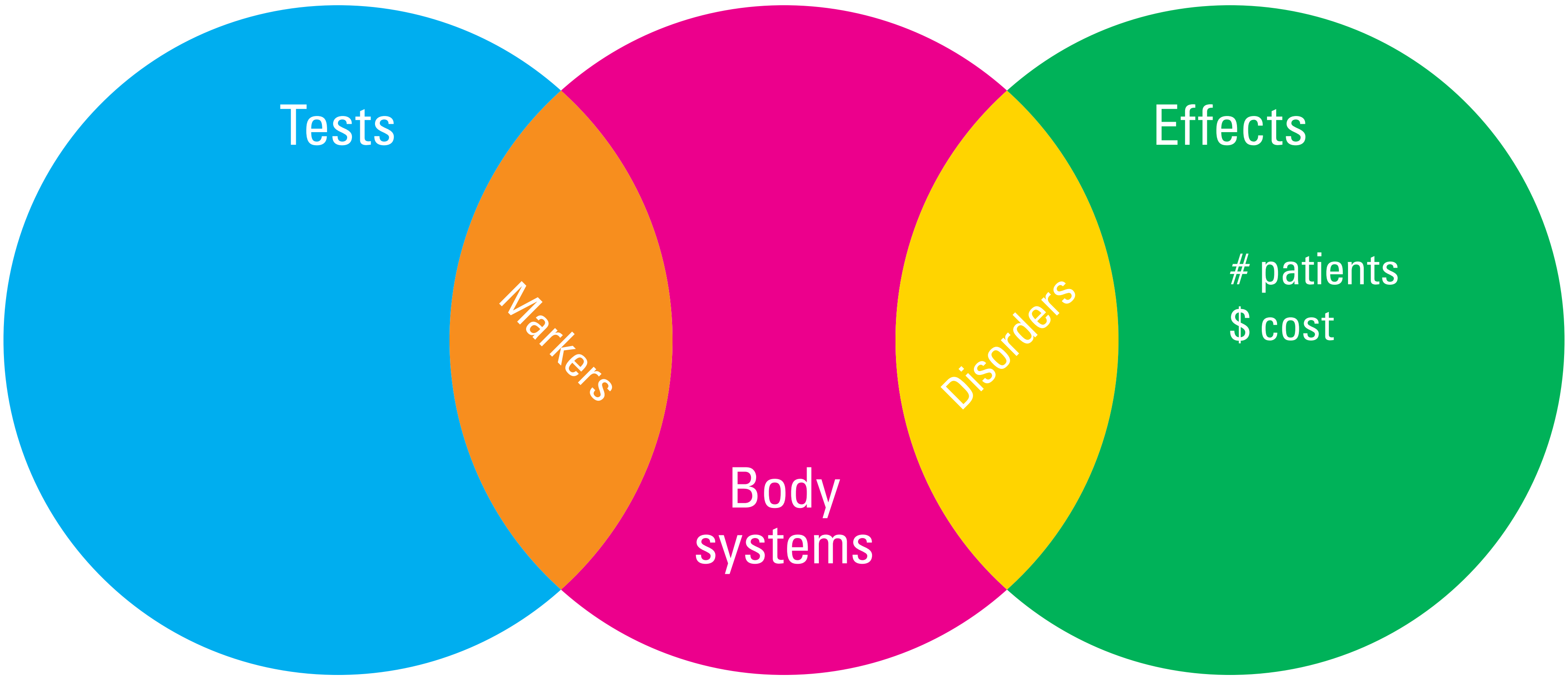
Disorders

Effects

Tests

The database provides a whole-systems view of well-being

This approach points to a unified future for health management



For example:

Cholesterol LDX

Total cholesterol
* in mg/dL

Desirable: < 200
Borderline high: 200–239
High: > 240

Cardiovascular

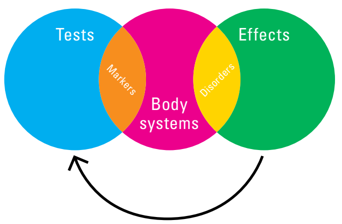
Blood: lipids

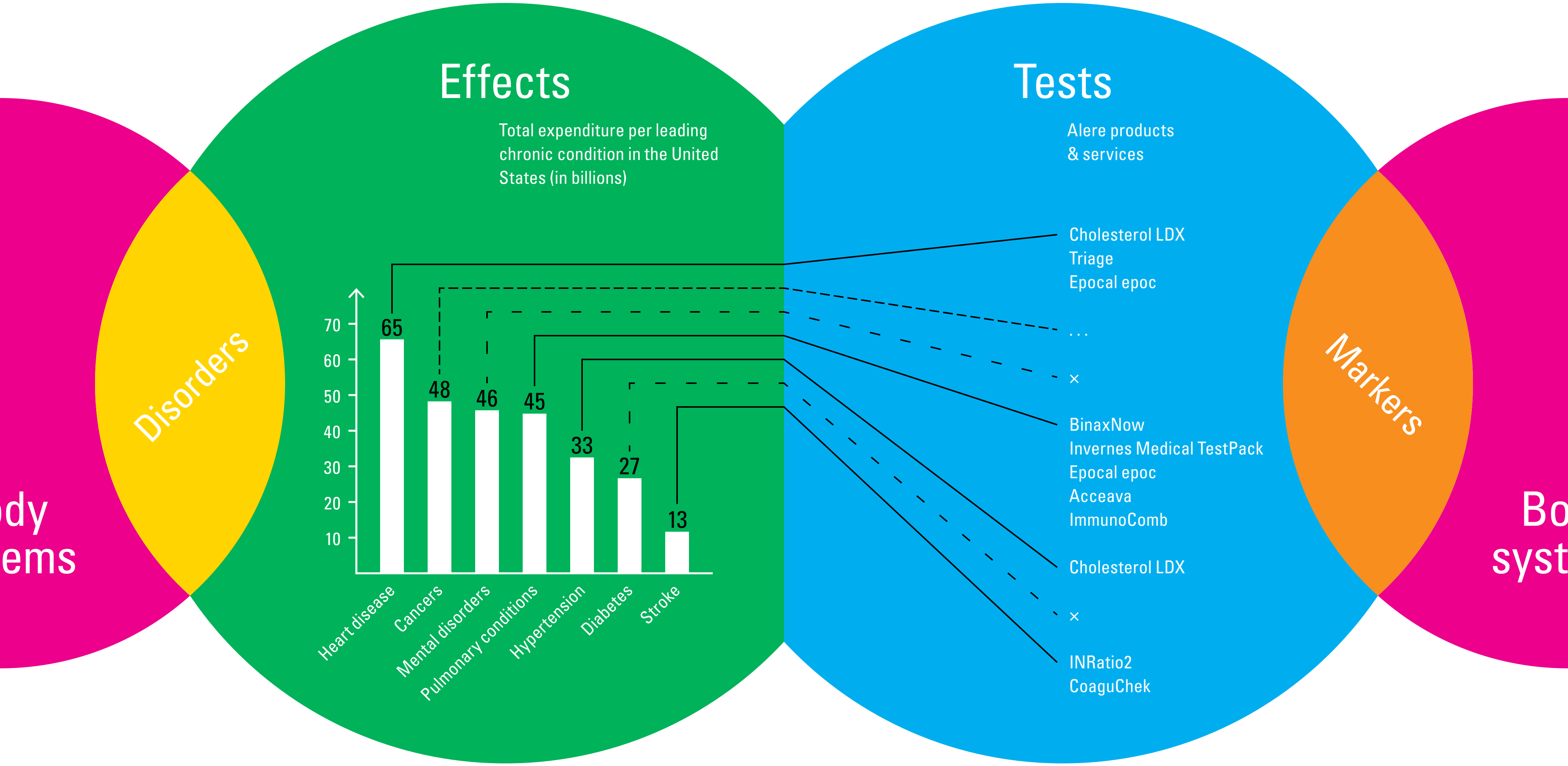
Hyper/hypo-cholester-olemia, coronary heart disease, heart failure

Hypercholesterolemia: 110 million
Coronary heart disease: 17.6 million
Heart failure: 5.8 million

This new database can help identify potential opportunities

It can ‘close the loop’ between effects and tests





Health is more than measuring chemicals

A whole-systems view should encompass more than chemical markers and consider how our actions, emotions, perceptions, and histories affect our overall health

Well-being

Physical factors

Markers of bodily homeostasis primarily measurable through blood, urine, and tissue

e.g.
prothrombin time
cholesterol
bone density

Activities

Things you do that alter your bodily chemistry in some way

e.g.
eating
physical activity
hydration

Psychological factors

Measures of health related to emotion and self-perception that are not easily quantified

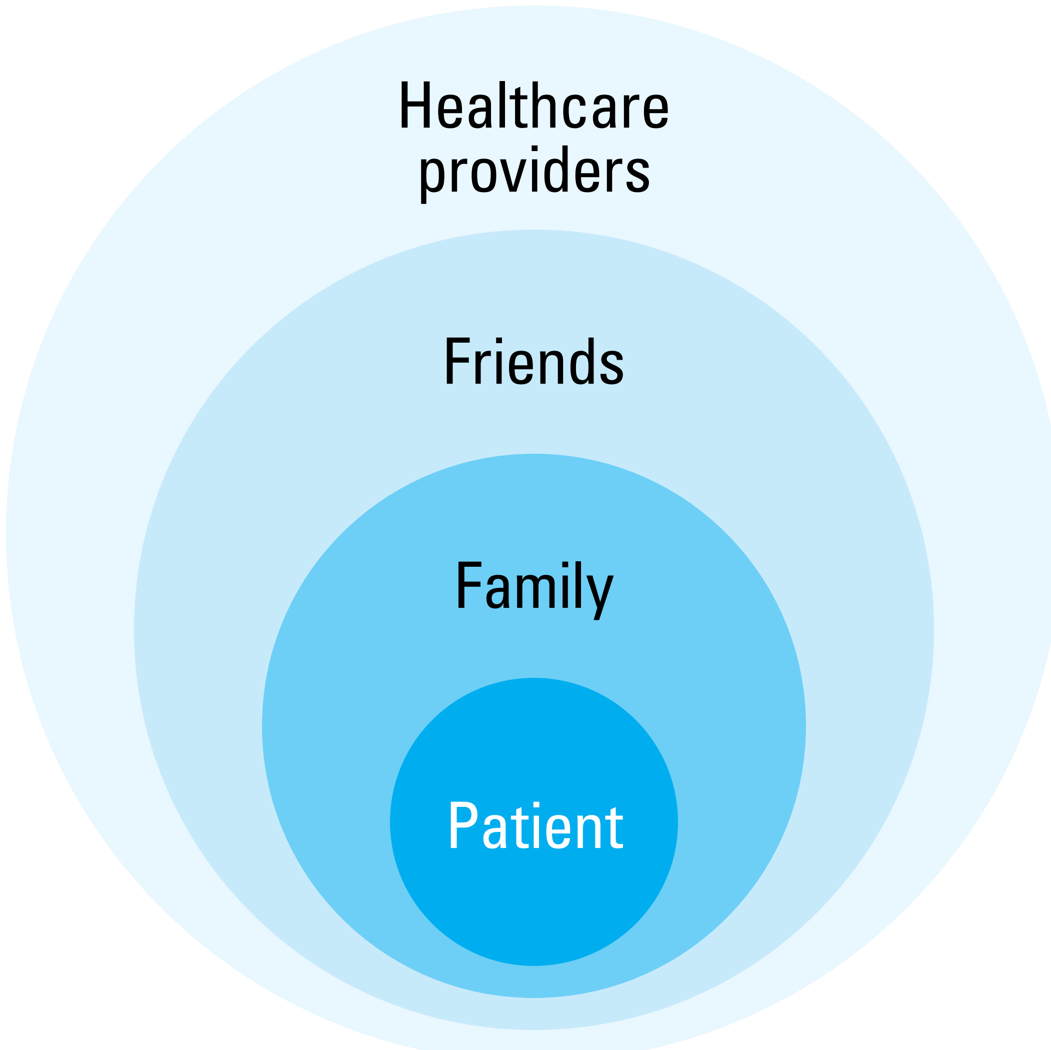
e.g.
sense of energy
stress
body image

Risk factors

Potential indicators and dangers related to your past and current life situation

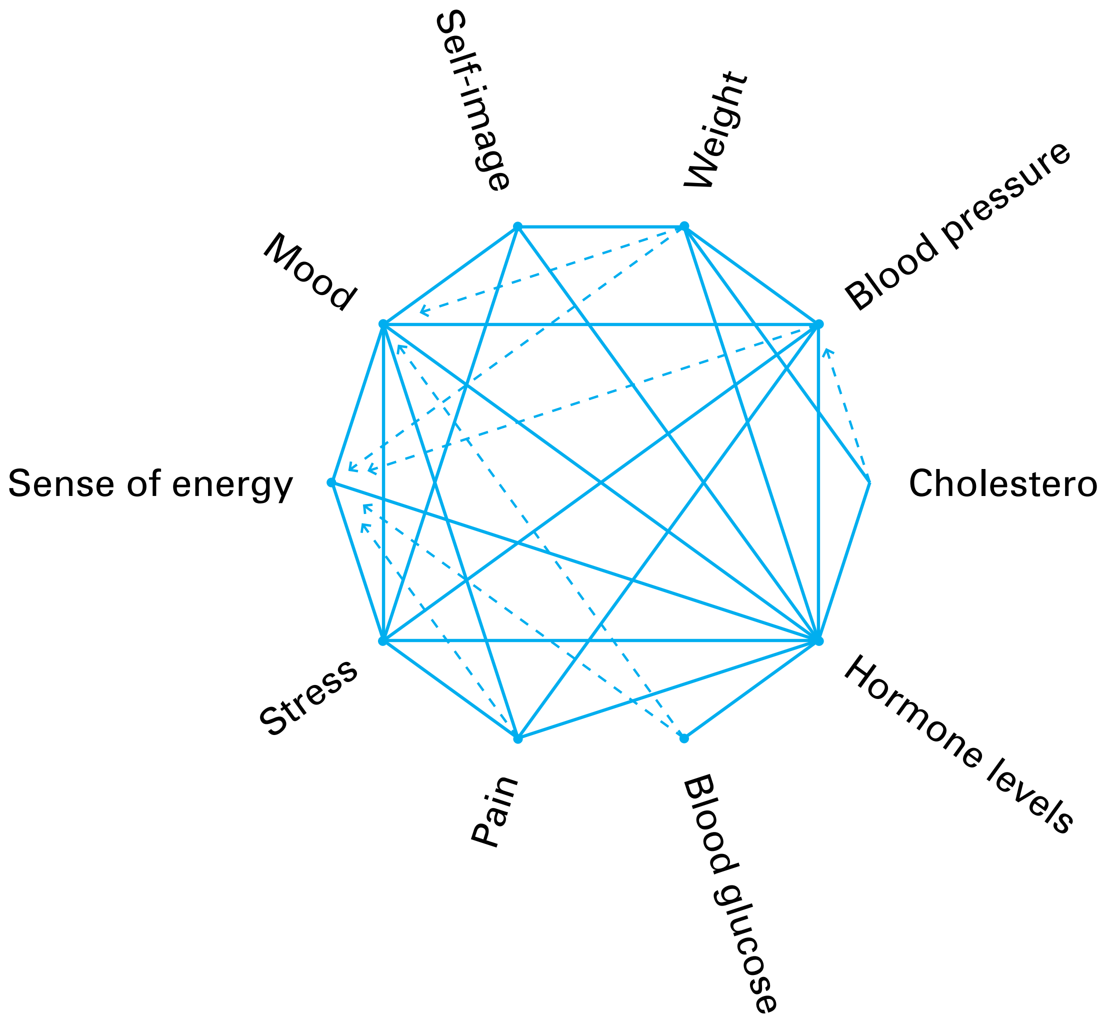
e.g
chronic activity
past incident
family history

A whole-systems view should show how an individual's network contributes to their health

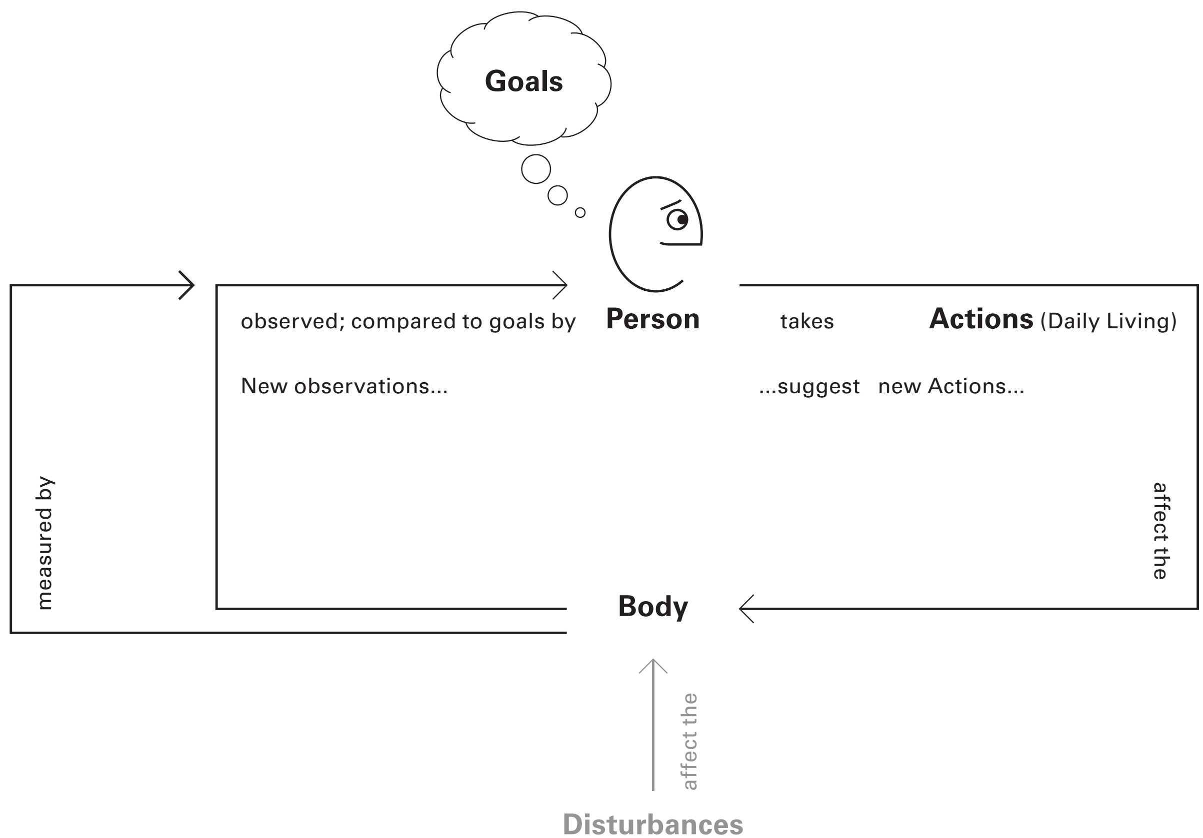


A very large number of factors contribute to wellbeing; many of them are richly interconnected.

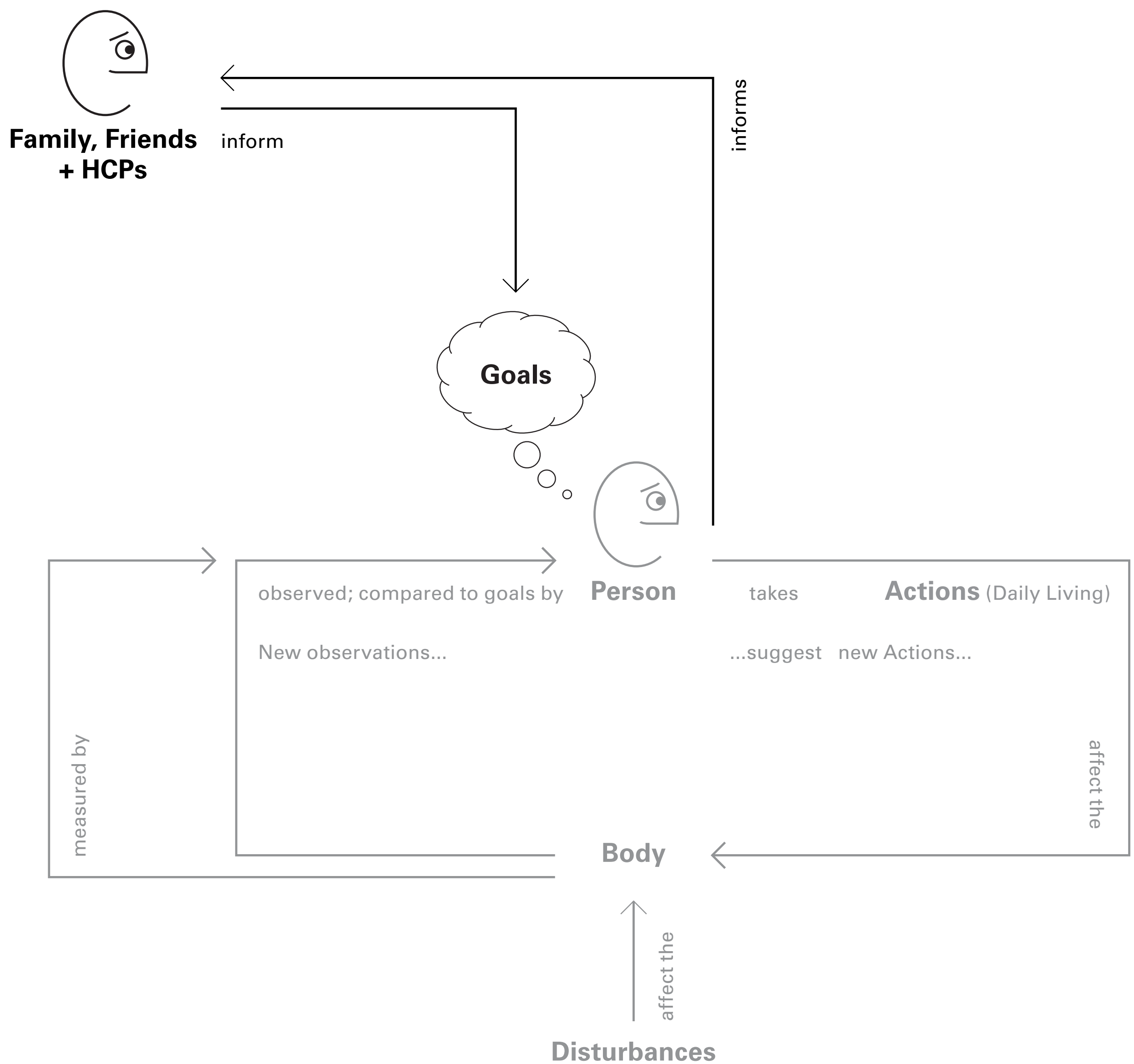
Modelling these relationships is complicated
but presents a truly massive opportunity for new understanding



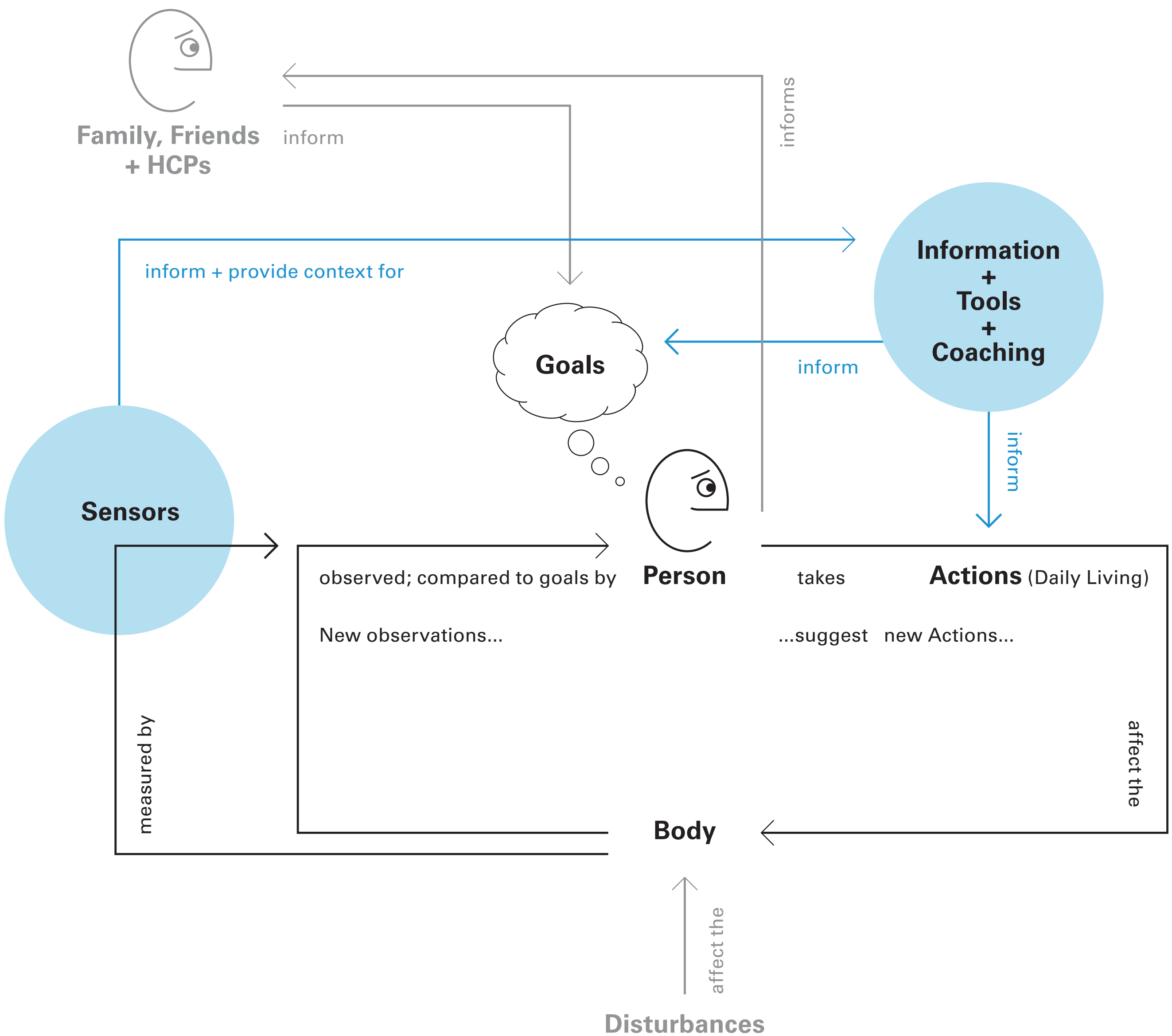
The feedback loop provides a conceptual model—imagine ‘Quantified Self (or diet tracking) for all of homeostasis’



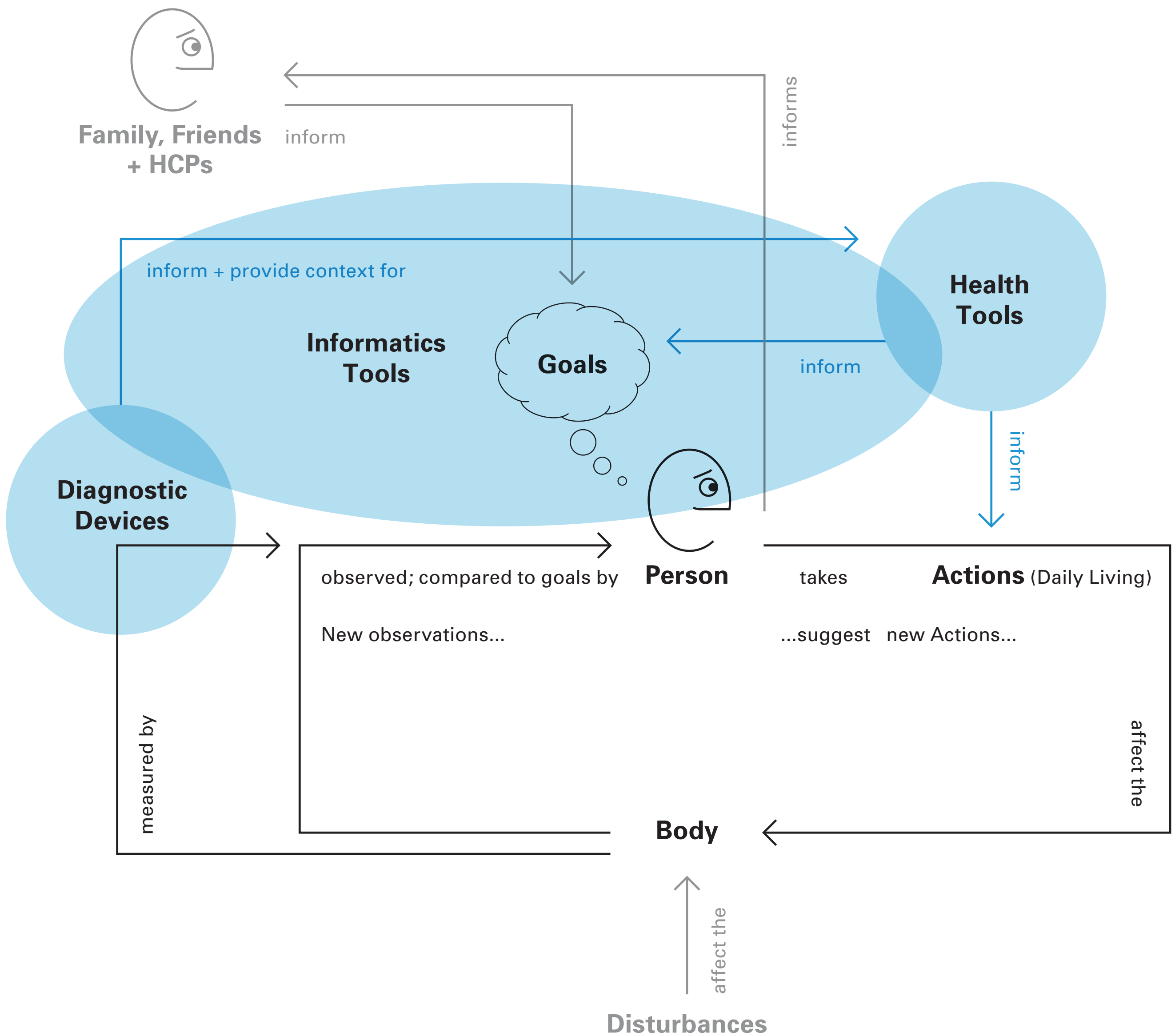
Individuals also need to connect to a wider circle, while controlling who sees what— imagine ‘Facebook for health’



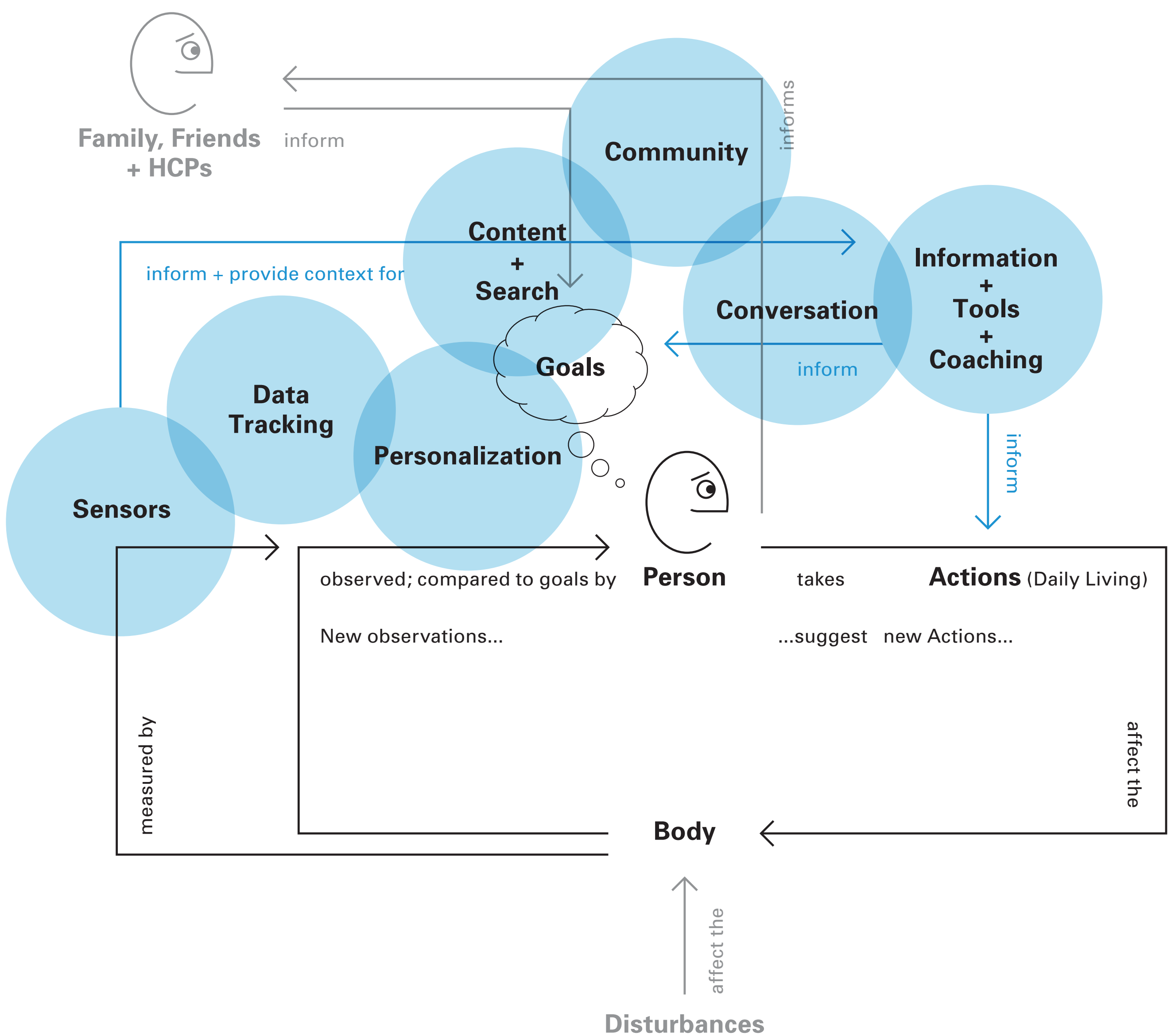
Connecting sensors with coaching offers a new blend of self-management or chronic care—imagine 'University of Phoenix for wellbeing'



Informatics tools can link devices, services, and people.

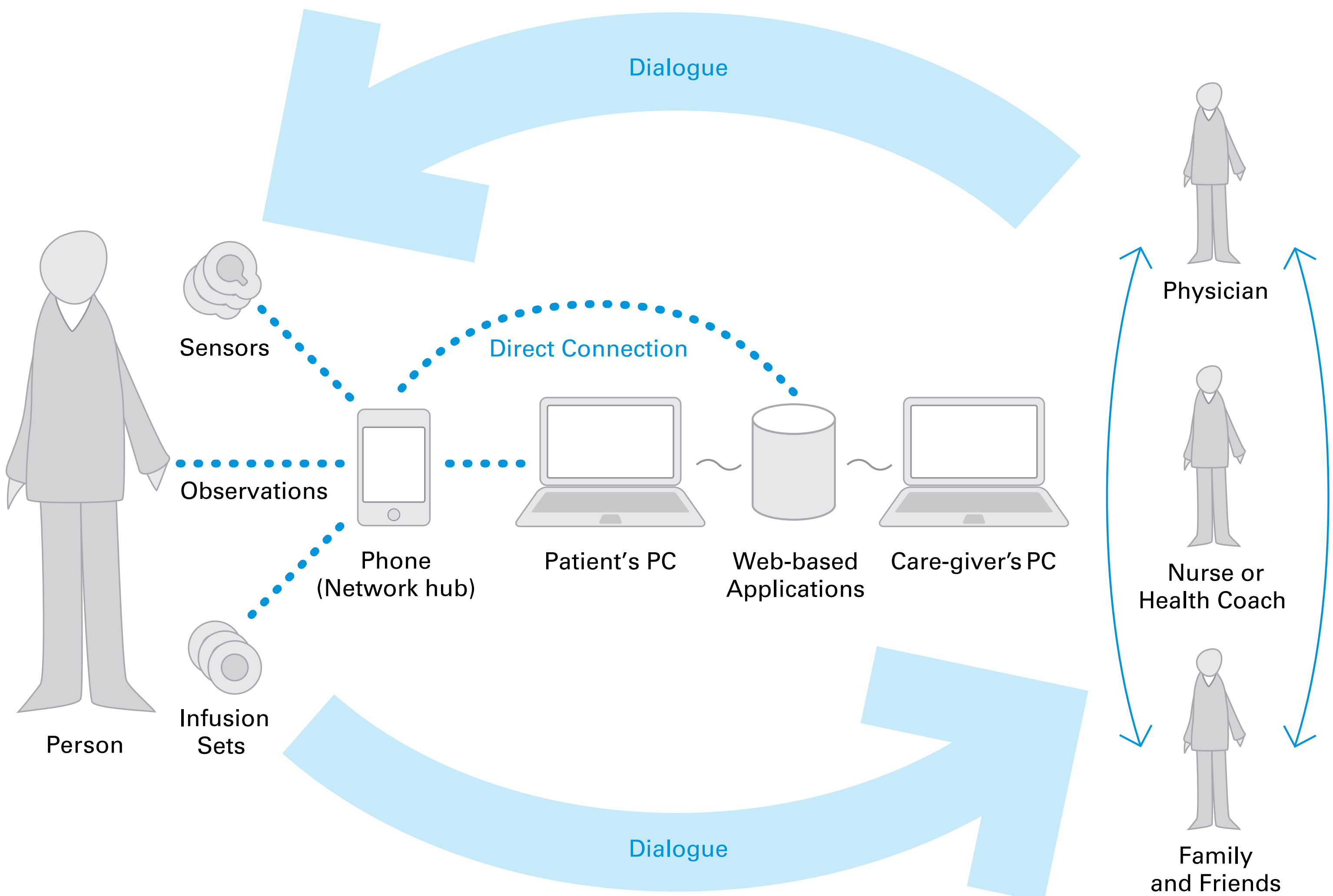


Informatics tools include five major areas.



Imagine 'QS + Facebook + University of Phoenix'

Individuals take a more active role in managing their own health (designing and running their own experiments)— while also engaging in more dialogue with others.



New tools can build a ladder to health + wellbeing.

Health + Wellbeing
↑ enable
Better Choices
↑ yield
Motivation + Validation
↑ yield
Conversations + Learning
↑ support
Data + Stories
↑ generate
Actions + Events

Part 5

A discussion

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