A Learning Health System to Transform Care and Health Equity

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"Nike knows how to use your data to sell you the right pair of shoes better than healthcare knows how to use your data to personalize your care"

# A Cancer Diagnosis brings MANY Questions
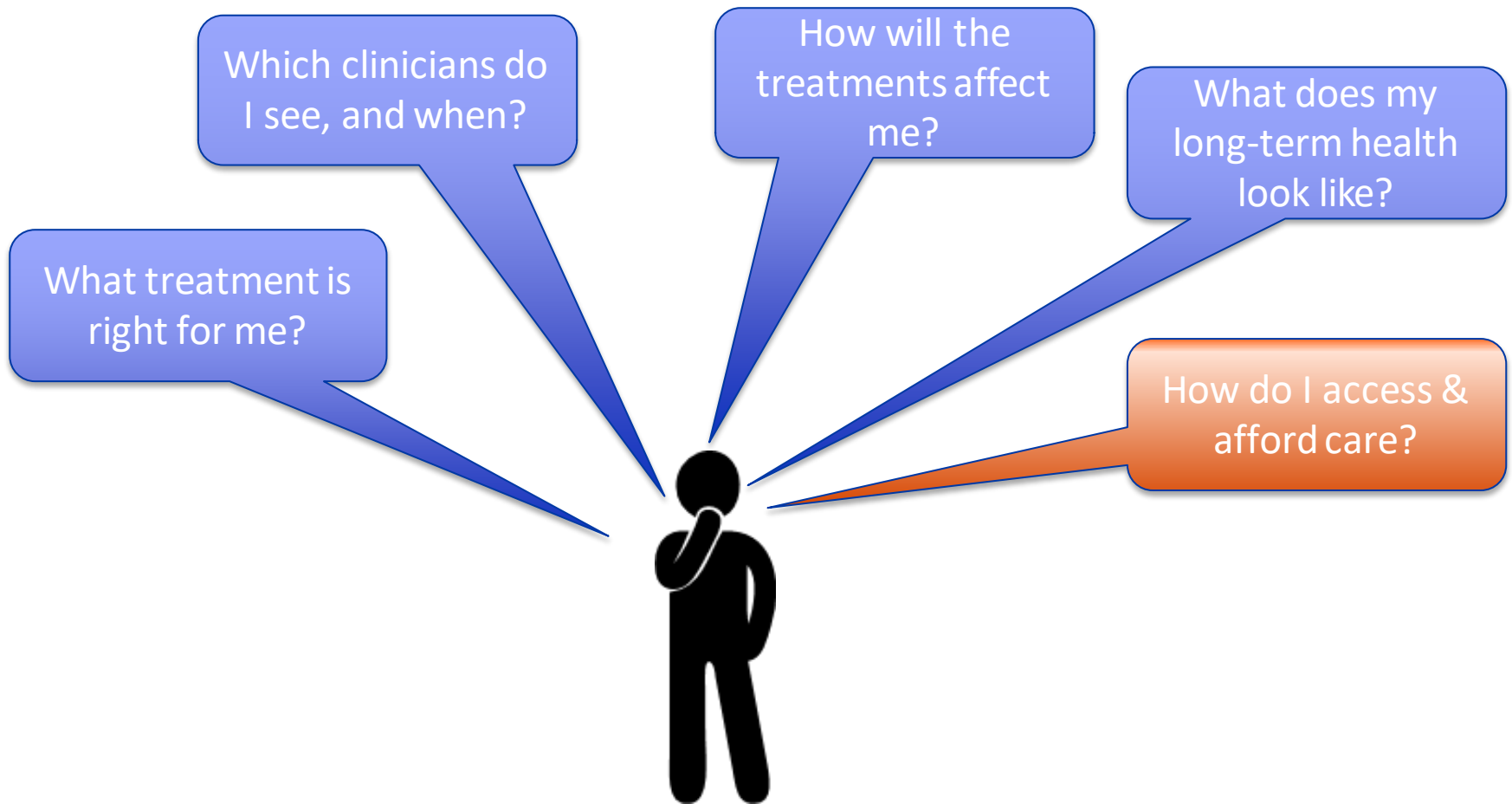
Answers are Complicated by Heterogeneity in Response to Treatment

- Cancer Therapeutics
- Toxicities
- Psychosocial Response to Cancer
- Impact of Cancer on Patient Function
- Follow-up Care Needs
- Social Determinants of Health

The Quest for Personalized Care Created a Data Explosion = Cognitive Overload & SLOWER Clinical Decisions
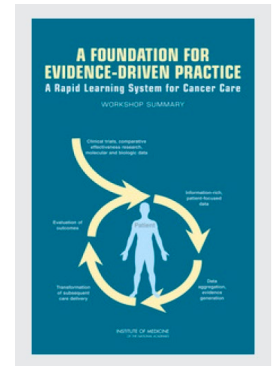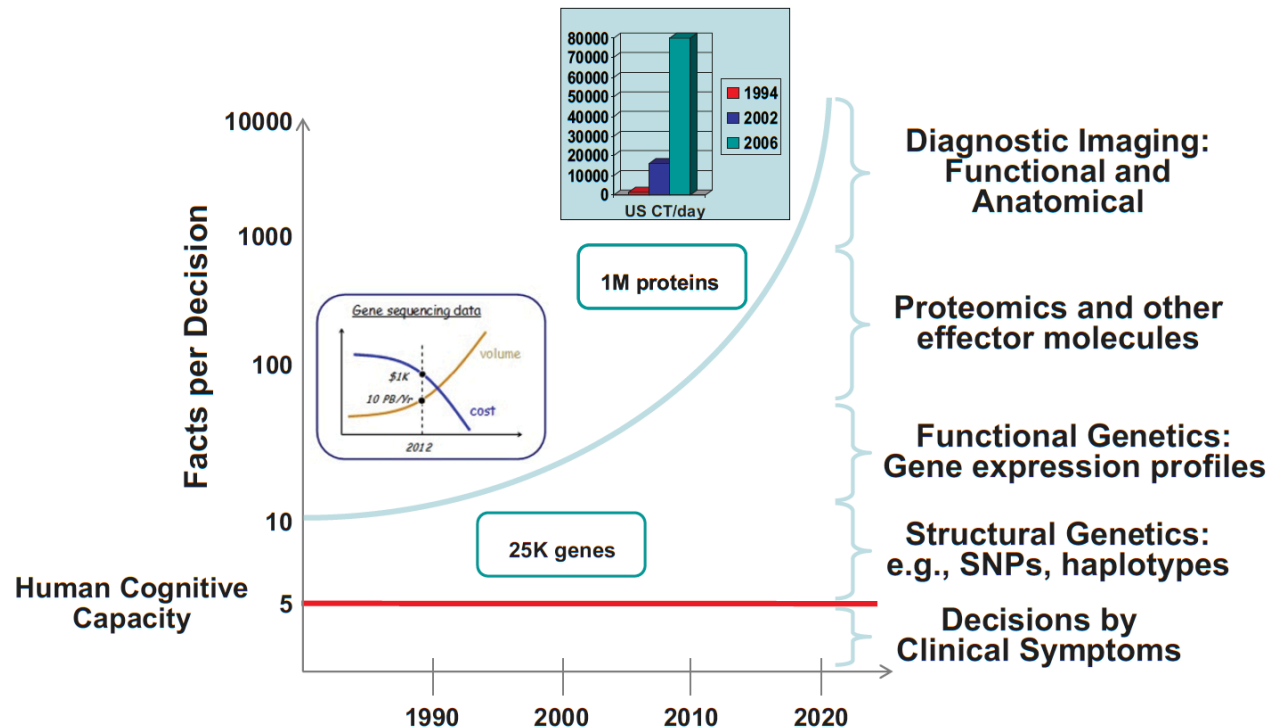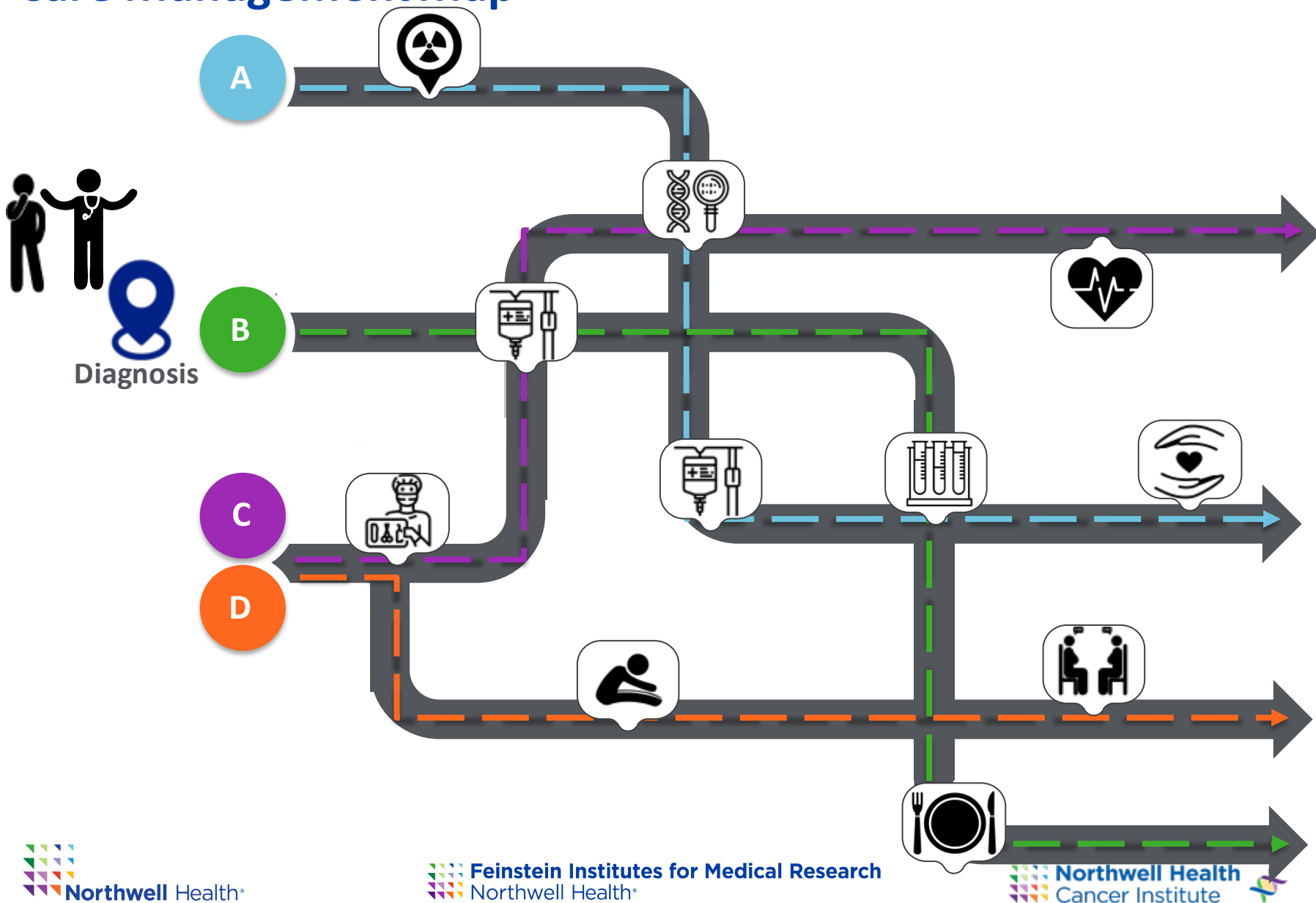

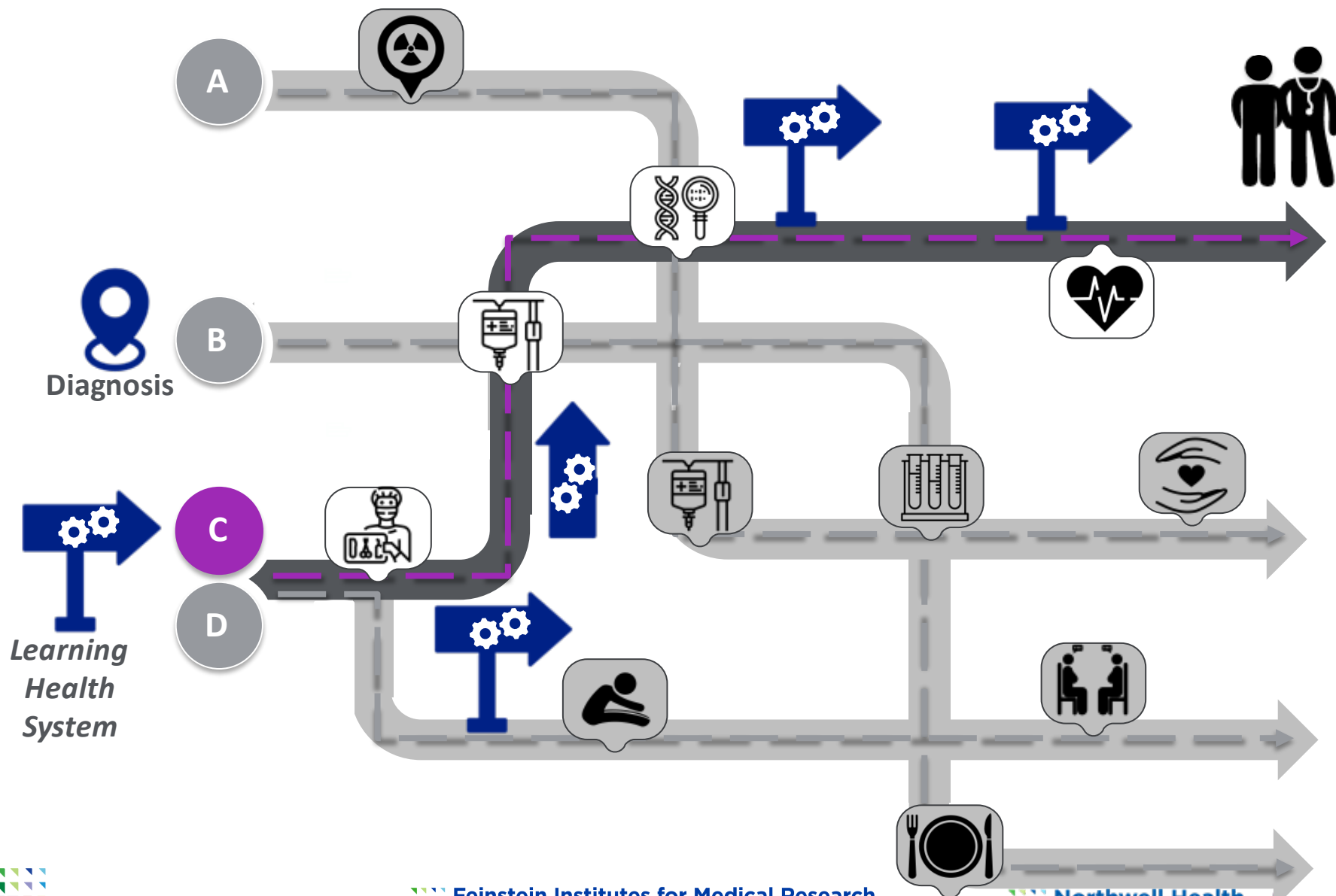FIGURE 3-2 Challenges to delivery of individualized clinical care are data explosion and cognitive overload, exceeding human cognitive capacity.

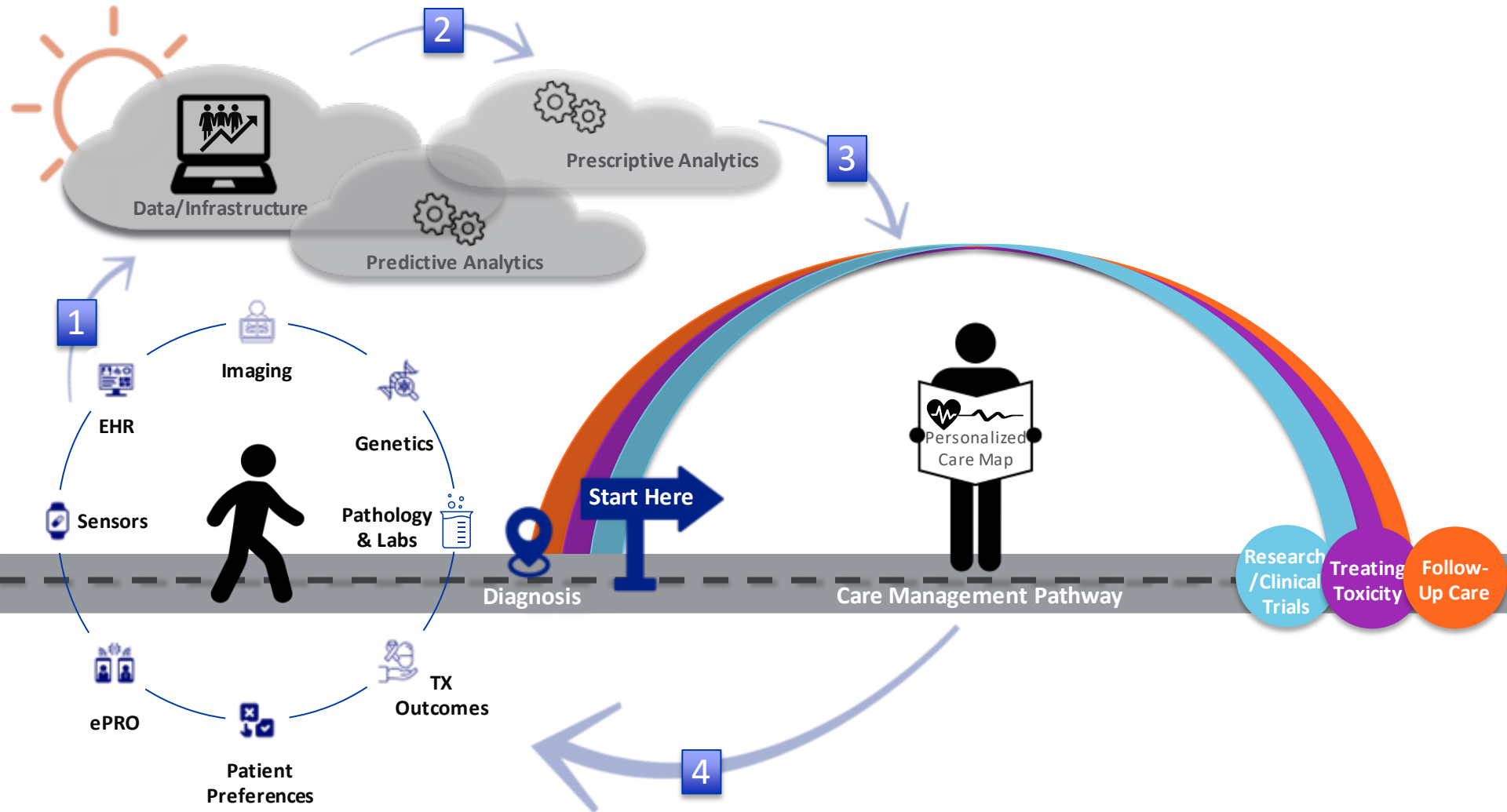SOURCE: Neti, 2009. Adapted from Stead, 2007, p. 19.

IOM 2010

The Current State of Cancer Care Cannot Specify a Long-term Care Management Map

New Standard of Personalized Cancer Care

The Learning Health System enables a seamless pathway of personalized care

Most Healthcare Systems Want to Develop Learning Health Systems but are Struggling

FIGURE 1

ONLY 15% OF ORGANIZATIONS ARE FULLY EQUIPPED TO MAKE QUICK DATA-DRIVEN DECISIONS

Most are building their capabilities, while a third lag behind
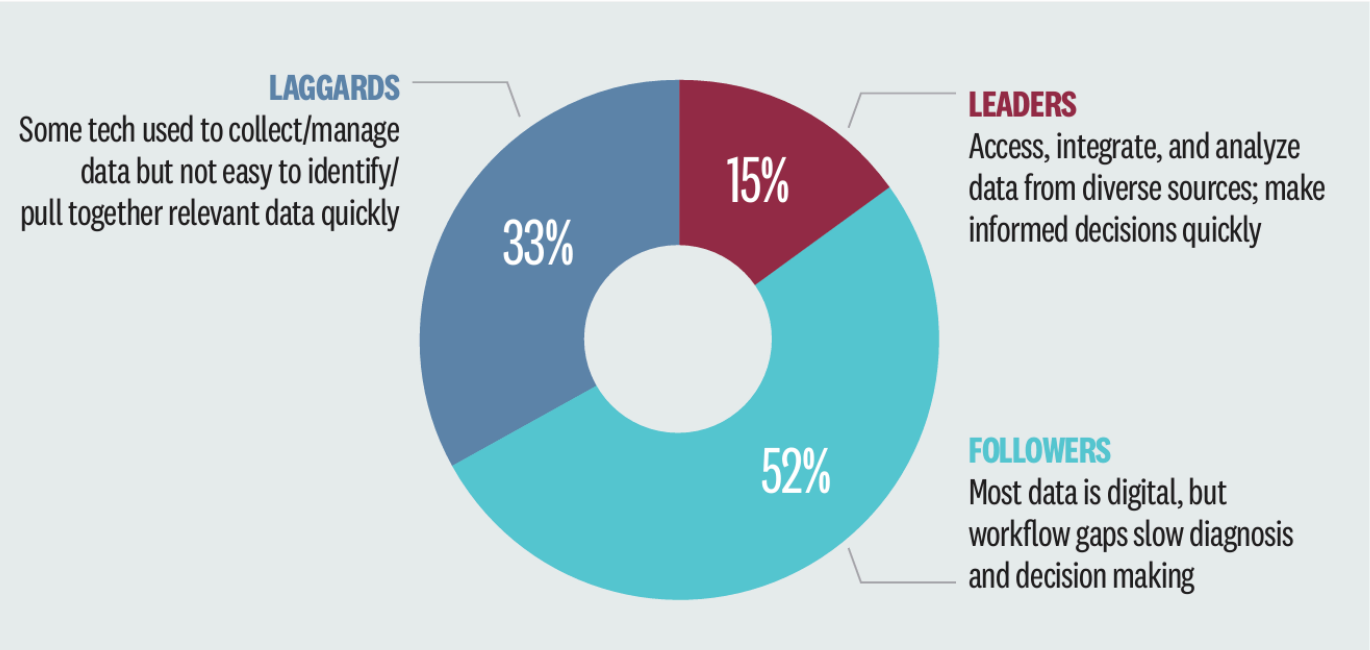
LAGGARDS
Some tech used to collect/manage data but not easy to identify/ pull together relevant data quickly

LEADERS
Access, integrate, and analyze data from diverse sources; make informed decisions quickly

15%

33%

52%

FOLLOWERS
Most data is digital, but workflow gaps slow diagnosis and decision making

SOURCE: HARVARD BUSINESS REVIEW ANALYTIC SERVICES SURVEY, APRIL 2019
Global survey of 742 health care leaders

Vision and Leadership are key

"The key enabler is leadership… that sets the direction, frames what you are trying to do, and then brings people along". --Enticott et al, BMC Health Services Research, 20, 1087, 2020

… But not sufficient

Lesson learned #1.
Involve many kinds of researchers, clinicians, patient advocates, leaders, and outside companies

A Data Ecosystem with a Longitudinal View of a Patient Requires Collaboration across Siloed Sectors and Stakeholders
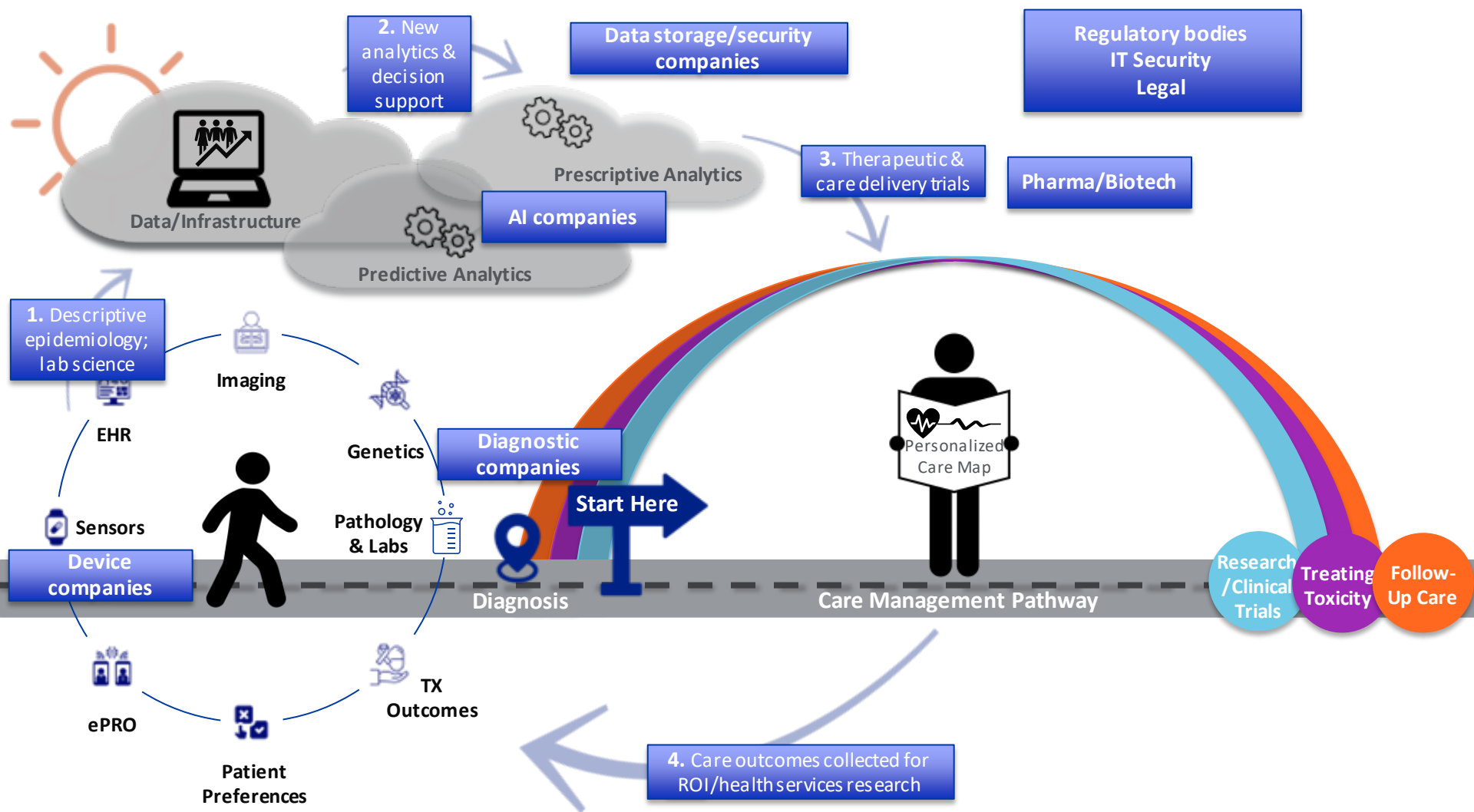
Lesson learned #2:
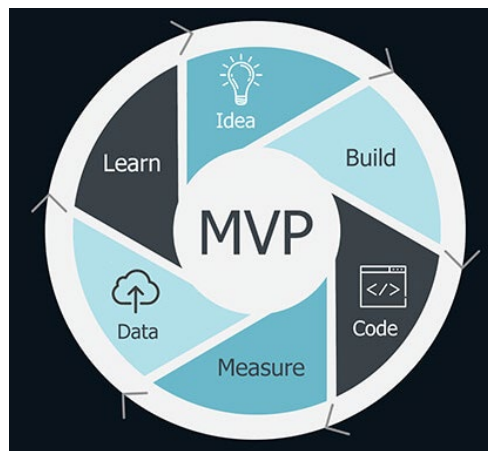# This big vision can be a tough sell. Need to focus on a use case with compelling ROI*

*e.g. nursing separation & hiring needs

First build the MVP, then pilot test in a few sites, evaluate, learn, innovate, and disseminate

Evaluate ROI to garner more resources for future improvements

Lesson learned #3.
Funding for building a connected data ecosystem is problematic and not in any one agency's mission
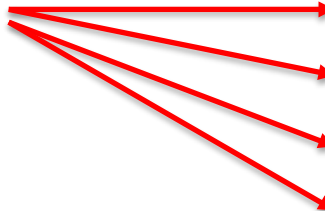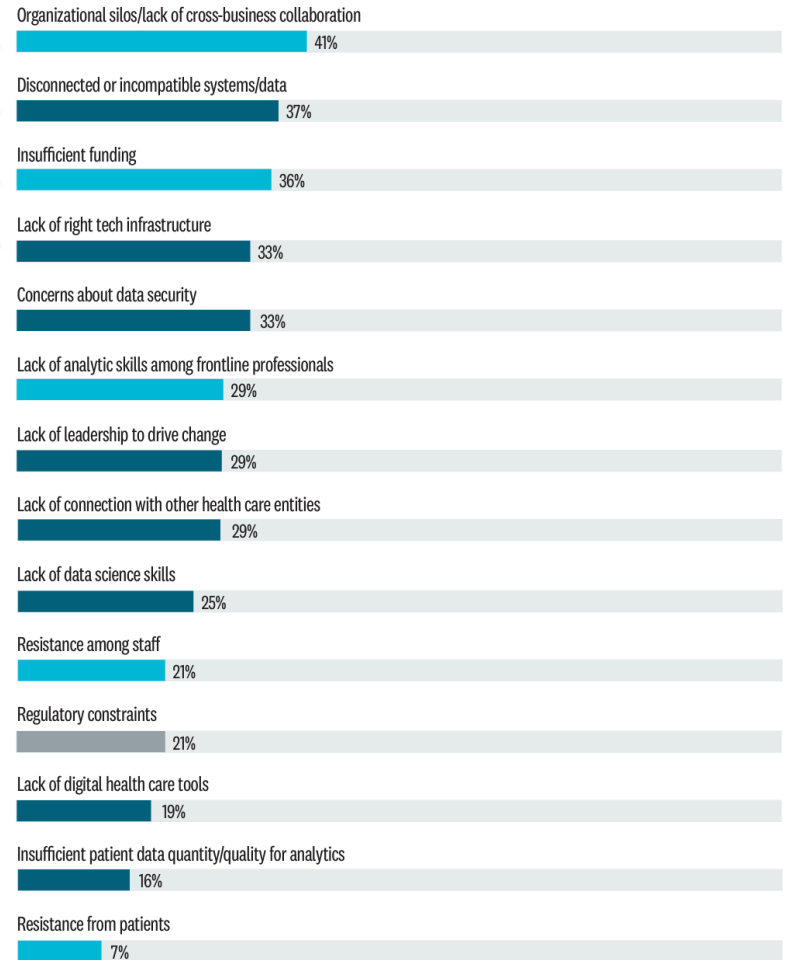
* These are the top barriers for everyone

FIGURE 6

SILOS—OF GROUPS, SYSTEMS, AND DATA—ARE HOLDING THINGS BACK

Health care organizations face a complex mix of hard and soft challenges

● PEOPLE: CULTURE AND SKILLS   ● DATA: SYSTEMS, TOOLS, HARDWARE

Organizational silos/lack of cross-business collaboration — 41%

Disconnected or incompatible systems/data — 37%

Insufficient funding — 36%

Lack of right tech infrastructure — 33%

Concerns about data security — 33%

Lack of analytic skills among frontline professionals — 29%

Lack of leadership to drive change — 29%

Lack of connection with other health care entities — 29%

Lack of data science skills — 25%

Resistance among staff — 21%

Regulatory constraints — 21%

Lack of digital health care tools — 19%

Insufficient patient data quantity/quality for analytics — 16%

Resistance from patients — 7%

SOURCE: HARVARD BUSINESS REVIEW ANALYTIC SERVICES SURVEY, APRIL 2019

Global survey of 742 health care leaders

Why Push On? Personalizing care with a Learning Health System creates ROI: the Quintuple Aim of Healthcare

- Timely Proactive Treatment
- Research/Clinical trial access
- Personalized Multi-disciplinary care

- Coordinated care diagnosis through follow-up
- Care Delivery that Overcomes Access Barriers

Patient Outcomes

Patient Experience

Health Equity

Happy Clinicians and Researchers

Efficiency & Lower Cost

- MD/APP practice at top of license
- Prioritize time for high acuity patients & research
- Build careers
- Decreased admin burden

- Appropriate healthcare utilization
- Effective use of APPs & Subspecialists/programs

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A Time of Moon Shots and Grand Challenges

THE WHITE HOUSE

Administration   Priorities   The Record   Briefing Room   Español   MENU

THE PRESIDENT AND FIRST LADY'S

CANCER MOONSHOT

ENDING CANCER AS WE KNOW IT

The Cancer Moonshot is mobilizing efforts toward achieving two clear goals that the President and First Lady set: To prevent more than 4 million cancer deaths by 2047 and to improve the experience of people who are touched by cancer.

ARPANET-H
ARPA-H Health Innovation Network

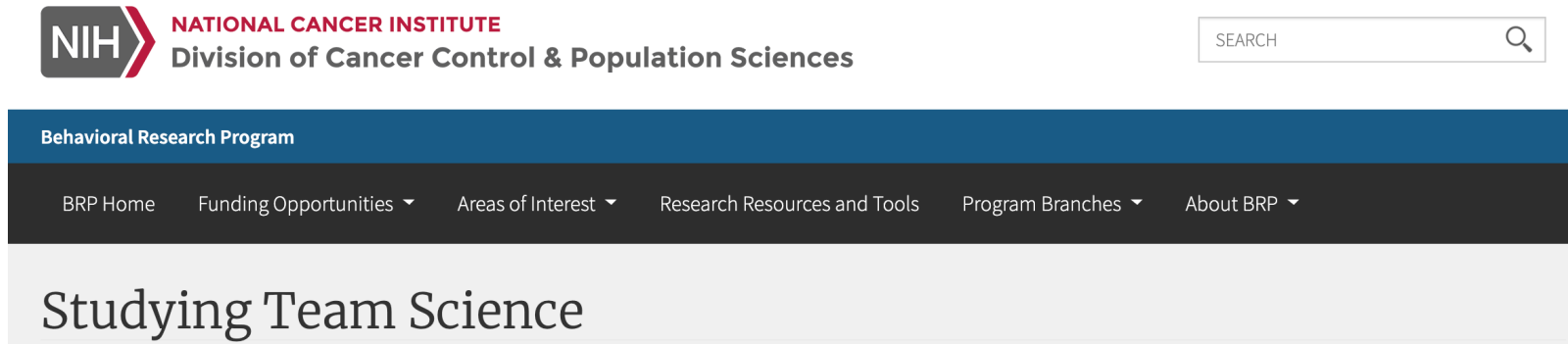**ARPA-H launches ARPANET-H: A nationwide health innovation network**

...mostly focused on novel therapeutics

"Nike knows how to use your data to sell you the right pair of shoes better than healthcare knows how to use your data to personalize your care"

Until we can better use our data, the best new therapeutics will fail!

Proposal: Make Progress Building a Learning Health System by Applying Lessons Learned from Stimulating Team Science

NATIONAL CANCER INSTITUTE
Division of Cancer Control & Population Sciences

SEARCH

Behavioral Research Program

BRP Home | Funding Opportunities ▾ | Areas of Interest ▾ | Research Resources and Tools | Program Branches ▾ | About BRP ▾

Studying Team Science

- Large funded transdisciplinary projects promoted collaboration and connection and focused on compelling use cases
- New scientific frontiers were explored
- Training components created a new workforce in hybrid fields
- Initially slow progress led to higher impact and productivity

https://cancercontrol.cancer.gov/brp/research/team-science-toolkit/about-scits/studying-team-science

We Can ONLY Meet These Goals by Working TOGETHER

My Ask*:

Trans-governmental funding for a collaboratory of 10 pilot sites that create functional data ecosystems with feedback loops & training programs, forming the backbone of a Learning Health System.

Deliverable: a blueprint for other health systems to follow
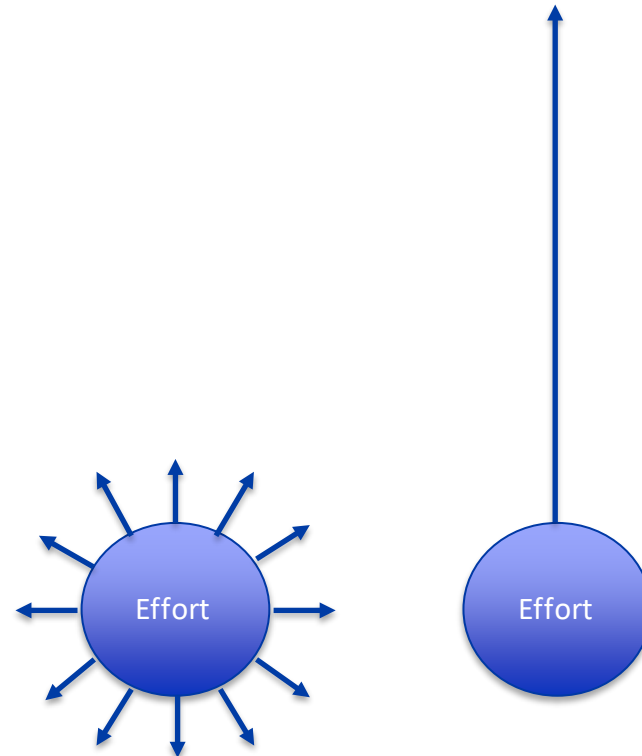
*Also suggested by Califf et al, *Am J Bioethics*, 2023

Effort

Effort

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4. National Cancer Institute, Lessons Learned from Studying Team Science: https://cancercontrol.cancer.gov/brp/research/team-science-toolkit/about-scits/studying-team-science

5. Califf, R., Faden, R., Kass, N., et al. Challenges in the ethics and implementation of Learning Health Care Systems. *The American Journal of Bioethics, 23:8*, 1-4 (2023).

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