Citizen & personal science

Eric Hekler

With thanks to:
Gary Wolf, Dana Lewis,
Mad Ball,Martijn De Groot, & Camille Nebeker

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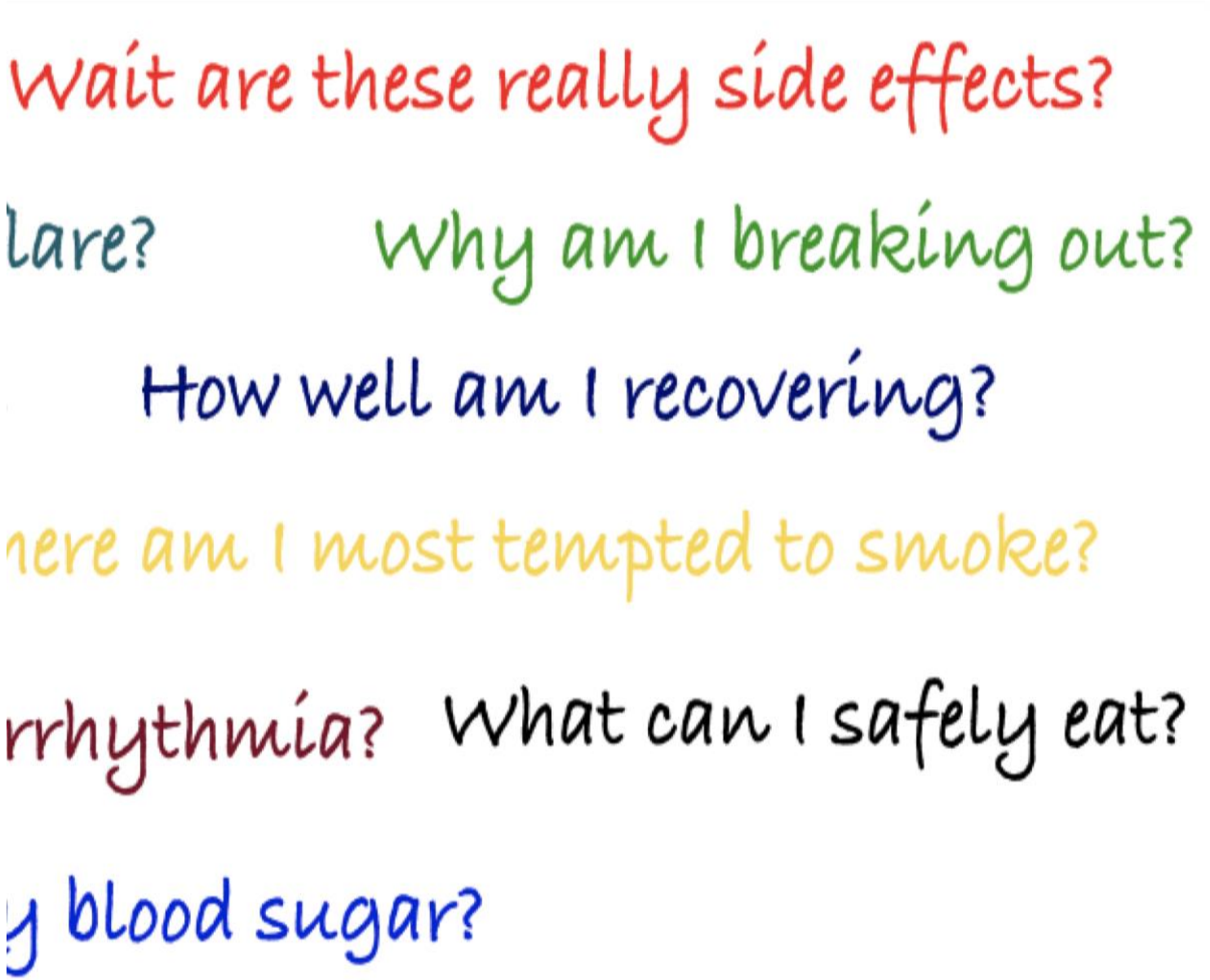
What is citizen science and personal science?

Citizen science

"the general public engagement in scientific research activities..."

European Commission, *Green Paper on Citizen Science for Europe: Towards a Society of Empowered Citizens and Enhanced Research*, 2014.

Personal science



Heyen, N. B. (2020). From self-tracking to self-expertise: The production of self-related knowledge by doing personal science. Public Understanding of Science, 29(2), 124–138. https://doi.org/10.1177/0963662519888757

https://medium.com/article-27

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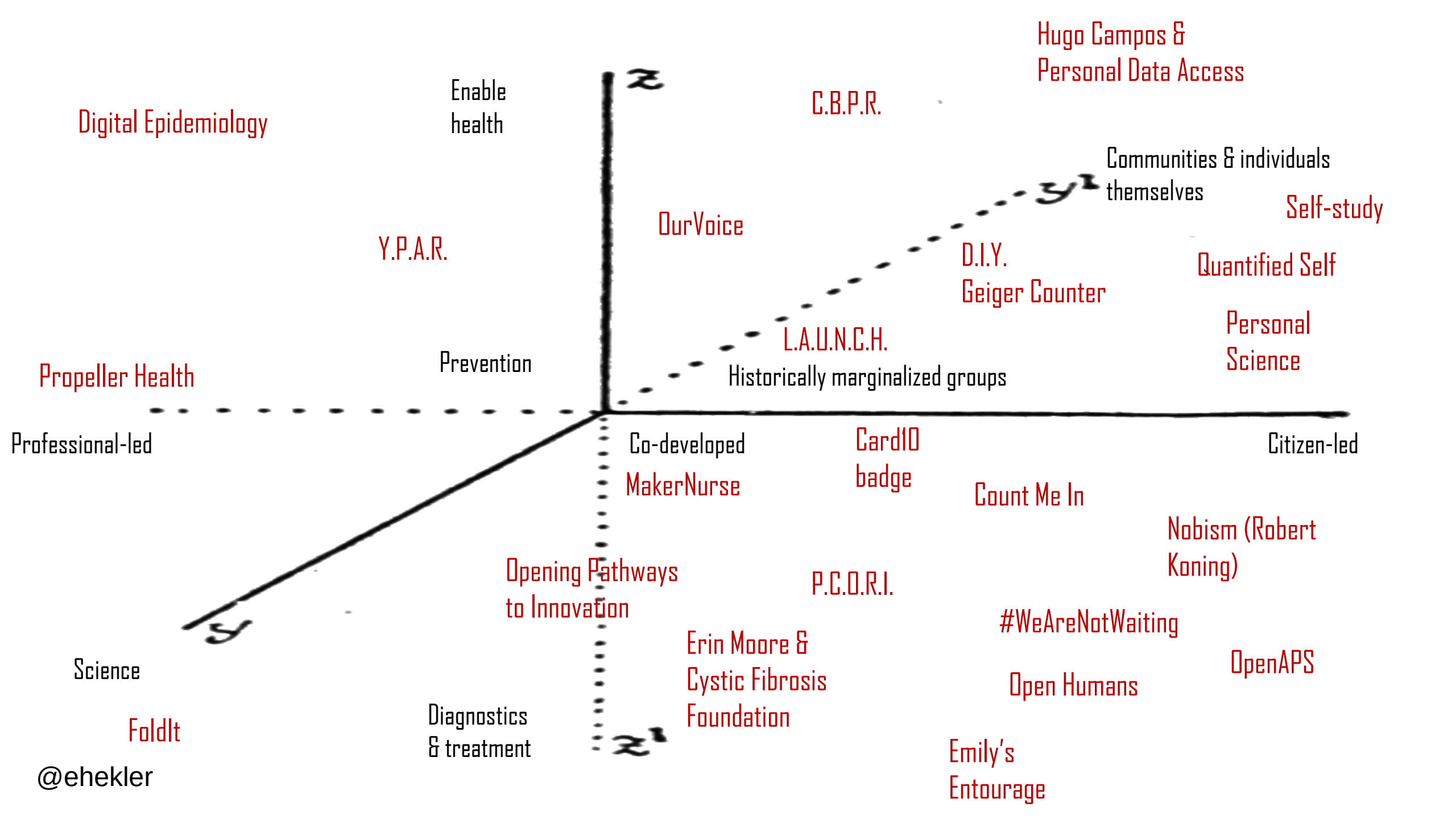
Hugo Campos &
Personal Data Access
Digital Epidemiology
Enable
health
C.B.P.R.
Communities & individuals
themselves
Self-study
OurVoice
Y.P.A.R.
D.I.Y.
Geiger Counter
Quantified Self
L.A.U.N.C.H.
Personal
Science
Prevention
Propeller Health
Historically marginalized groups
Professional-led
Co-developed
Citizen-led
CardIO
badge
MakerNurse
Count Me In
Nobism (Robert
Koning)
Opening Pathways
to Innovation
P.C.O.R.I.
#WeAreNotWaiting
Erin Moore &
Cystic Fibrosis
Foundation
OpenAPS
Science
Open Humans
Diagnostics
& treatment
FoldIt
Emily's
Entourage
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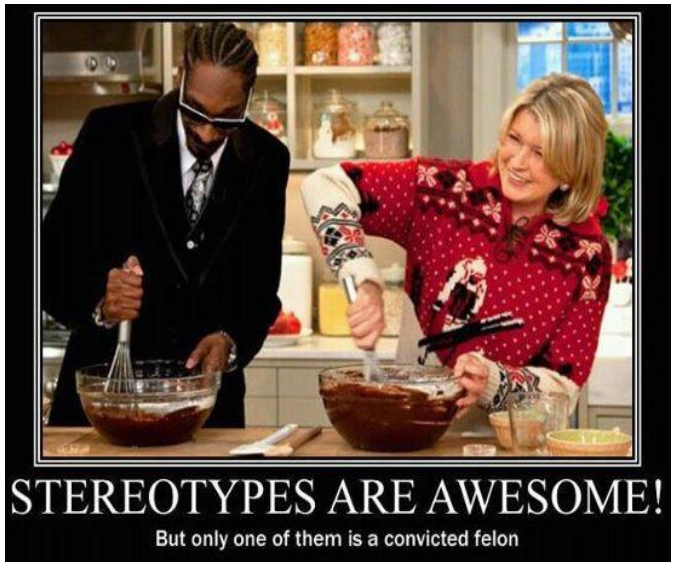
Why does it matter?

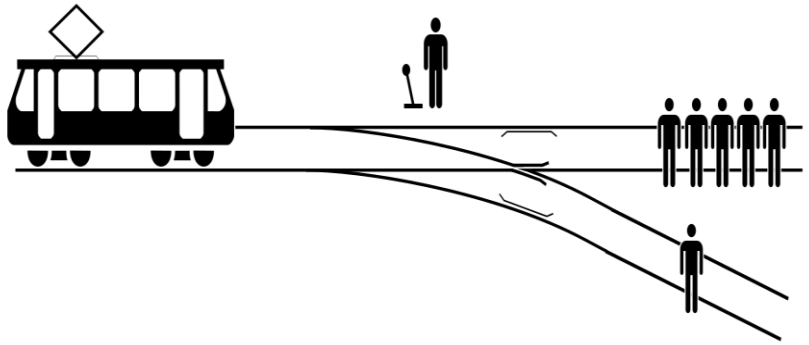
Allows us to see possible biases of professional science

Stereotyping



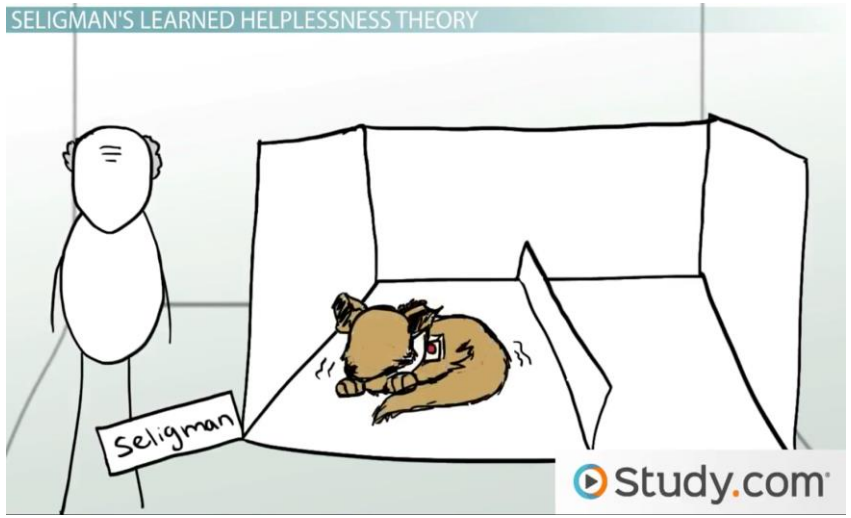
Flickr-Bob Morris

Omission Bias



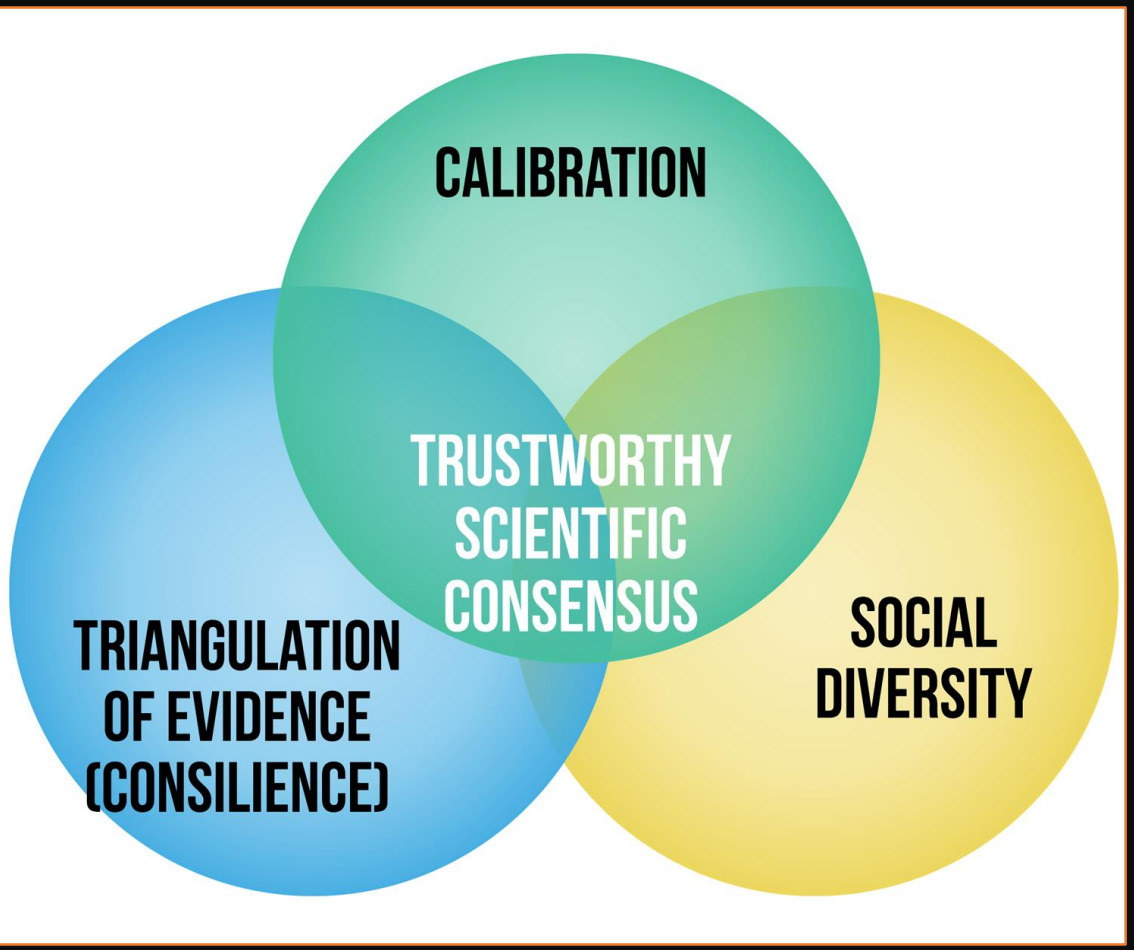
https://en.wikipedia.org/wiki/Trolley_problem

Learned Helplessness



https://study.com/academy/lesson/how-seligmans-learned-helplessness-theory-applies-to-human-depression-and-stress.html

Raises questions about trustworthiness of scientific consensus



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Boaz Miller (2013) When is consensus knowledge based? Distinguishing shared knowledge from mere agreement. *Synthese* 190(7):1293-1316.

Asks us to go beyond pure science into "ought" thinking

Is

- Science
- Facts
- Past and present

Ought

- Ethics and morality
- Values & principles
- Future

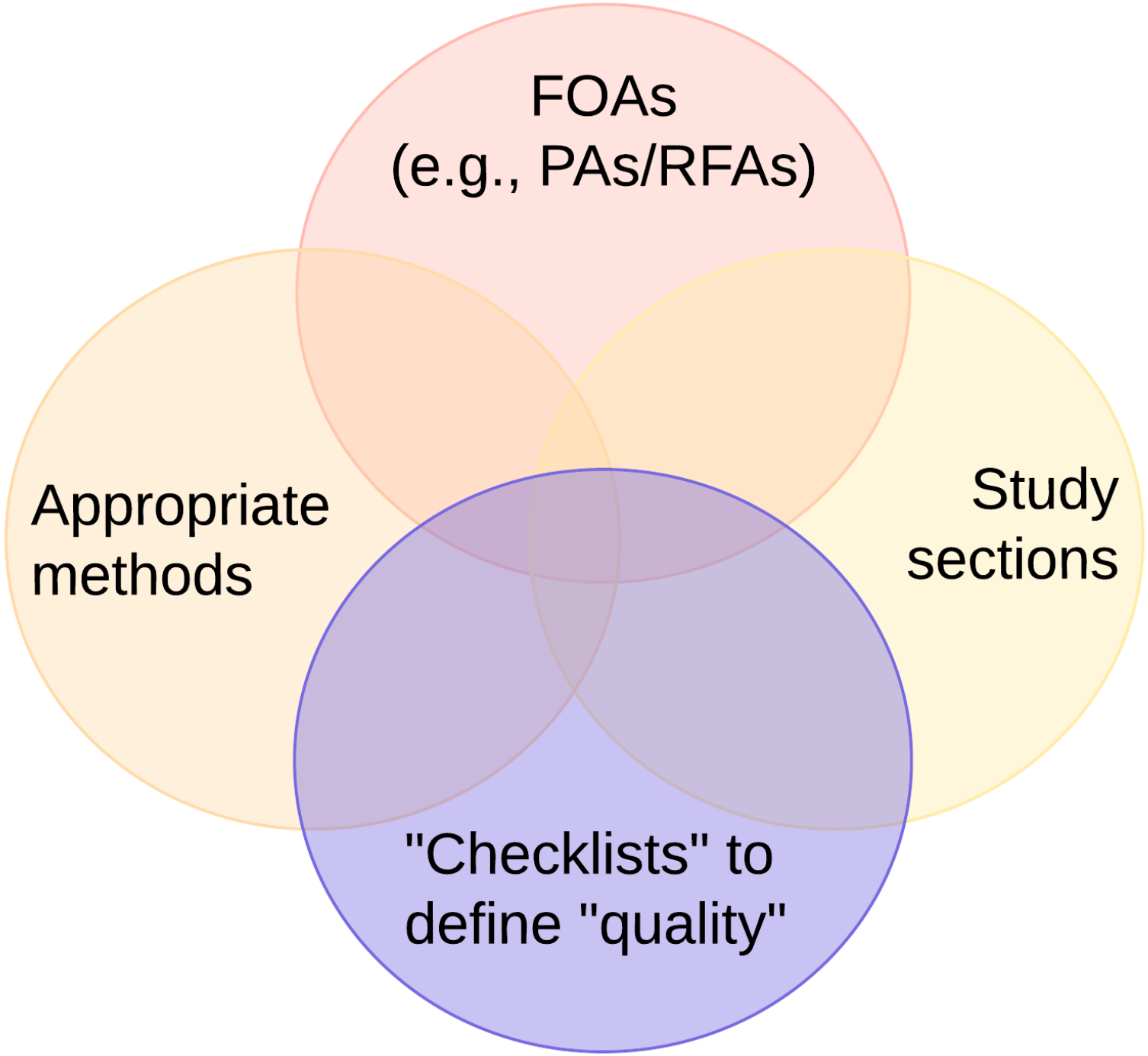
https://en.wikipedia.org/wiki/Is%E2%80%93ought_problem

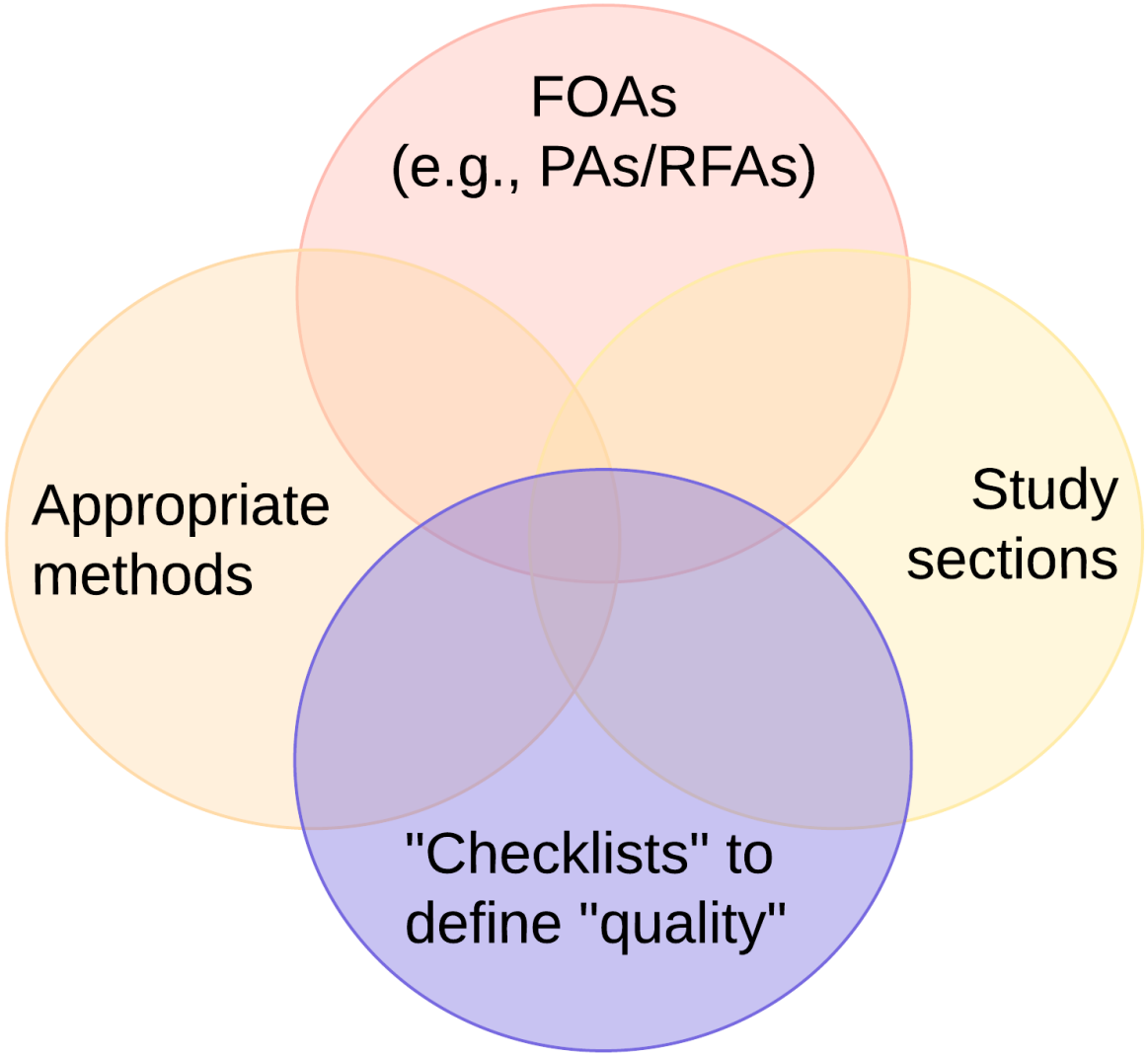
What should the NIH do?

Recognize some big questions and work on them

- How might we improve professional scientists' awareness of systemic implicit biases that, unintentionally, may compromise our capacity to support those we serve with our science?
- How do we, unintentionally, compromise equitable participation, contribution, and benefit from the applied sciences? How might we improve equity in science?
- How might we increase the trustworthiness of scientific consensus via diversifying people contributing and our methods without compromising our capacity to calibrate towards consensus?
- How do evidence and values interact effectively? How might we we bridge "is" and "ought" within the NIH and beyond?

Target four things





- Methods
  - Create & expand on NIH-acknowledged best-practice methods in citizen and personal science along with open science practices.
- Quality checklist
  - Build appropriate "checklists" of quality that a study section could use to ensure rigorous use of these methods while not compromising fundamental epistemological requirements of a given approach.
- Study sections
  - Create new study section(s), filled with a diversity of citizen & personal scientists plus traditional professionals who, together, support rigor in this type of science.
- FOAs
  - Create FOAs that legitimize and fund a wider range of contributors (e.g., participant-led work) and methods.

Thank you for your presence and attention.

Universal Declaration of Human Rights

Article 27

"Everyone has the right to participate…
[and] share in scientific advancement and its benefits…"

"Toda persona tiene derecho a tomar…y a participar en el progreso científico y en los beneficios…"

https://www.un.org/en/universal-declaration-human-rights/

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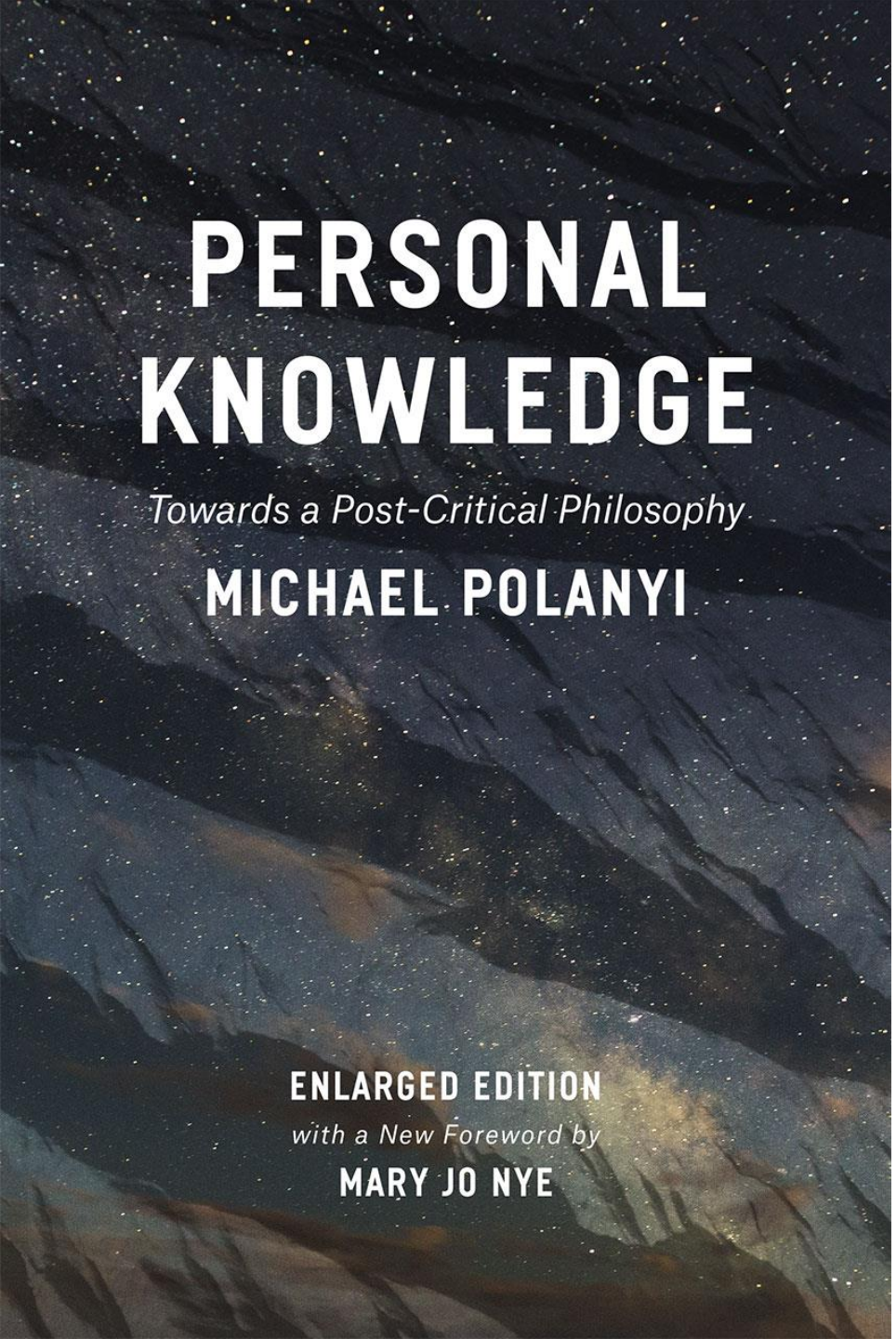
With thanks to Gary Wolf, Mad Ball, Dana Lewis, Martijn De Groot, Camille Nebeker, and others.

For more information on the link between Article 27 and personal science" see: https://medium.com/article-27

Extra slides

(Only used for discussion, if needed)



- Proposition:
  - Language (including mathematics)=representational system
  - Representational systems≠reality
  - Data=representations of observations made by an observer.
  - Data≠reality
  - Personal Knowledge/tacit knowledge is a human's link to reality and grounds observations, including data.
- Conclusion
  - Personal knowledge is the foundation of science
- Implication
  - "Facts" cannot be separated from the observer
  - Objectivism is not possible.
  - The observer (scientist) is an essential part of the scientific process
  - Observer should strive for de-fusion over objectivism (empirical)
  - Observer brings stories, which enable imagination, structure, and what if possibilities
  - These structures are what can be offered to invite others to find build capacity to experience and enact different possibilities of description, prediction, and control of ones' context

Peer-Reviewed Literature & Studies on DIY Closed Loop

- **DM Lewis**, S Leibrand. How a DIY Artificial Pancreas Built by a Patient Makes New Tools Available for Clinicians. DIABETES 64, A638-A638.
- **D Lewis,** S Leibrand. Real-world use of open source artificial pancreas systems. Journal of Diabetes Science and Technology 10 (6), 1411-1411.
- Lee JM, Newman MW, Gebremariam A, Choi P, **Lewis D**, Nordgren W, Costik J, Wedding J, West B, Gilby NB, Hannemann C, Pasek J, Garrity A, Hirschfeld E. Real-World Use and Self-Reported Health Outcomes of a Patient-Designed Do-it-Yourself Mobile Technology System for Diabetes: Lessons for Mobile Health. Diabetes Technology & Therapeutics 19 (4), 209-219.
- Ball MP and **Lewis DM**. "The Open APS Data Commons (OpenAPS + Open Humans)." Poster. 2017 Sage Bionetworks Global Assembly. DOI: 10.6084/m9.fig
- **Lewis DM,** Leib 2016;65(suppl 1).
- **D Lewis**. Setting e and Technology 12(
- White K, Gebre Media Community for
- Provenzano V, C 2018;67(suppl 1). Available at:
- Choi SB, Hong E abetes. 2018;67(suppl 1
- Crocket, H. Lear
- **Lewis DM**, Swain RS, Donner TW. Improvements in A1C and time-in-range in DIY closed-loop (OpenAPS) users. Diabetes. 2018;67(suppl 1). Available at: https://doi.org/10.2337/db18-352-OR
- **Lewis DM**, Leibrand S, Street TJ & Phatak SS. Detecting Insulin Sensitivity Changes for Individuals with Type 1 Diabetes. Diabetes. 2018;67(suppl 1). Available at: https://doi.org/10.2337%2Fdb18-79-LB
- Petruzelkova, L., Soupal, J., Plasova, V., Jiranova, P., Neuman, V., Plachy, L., … Obermannova, B. (2018). Excellent Glycemic Control Maintained by Open-Source Hybrid Closed-Loop AndroidAPS During and After Sustained Physical Activity. *Diabetes Technology & Therapeutics*. https://doi.org/10.1089/dia.2018.0214
- Litchman ML, **Lewis D**, Kelly LA, Gee PM. Twitter analysis of #OpenAPS DIY artificial pancreas technology use suggests improved A1C and quality of life [published online ahead of print September 10, 2018]. J Diabetes Sci Technol. doi:10.1177/1932296818795705
- **Lewis, D.** History and Perspective on DIY Closed Looping [published online ahead of print September 10, 2018. J Diabetes Sci Technol. doi:10.1177/193229681880830

(75+% of the studies & publications are done by, or led by, patients)

1:9:90 – a universal community model

1% of People Create Content

9% Share and Repackage

90% Listen and Learn

https://en.wikipedia.org/wiki/1%25_rule_(Internet_culture)

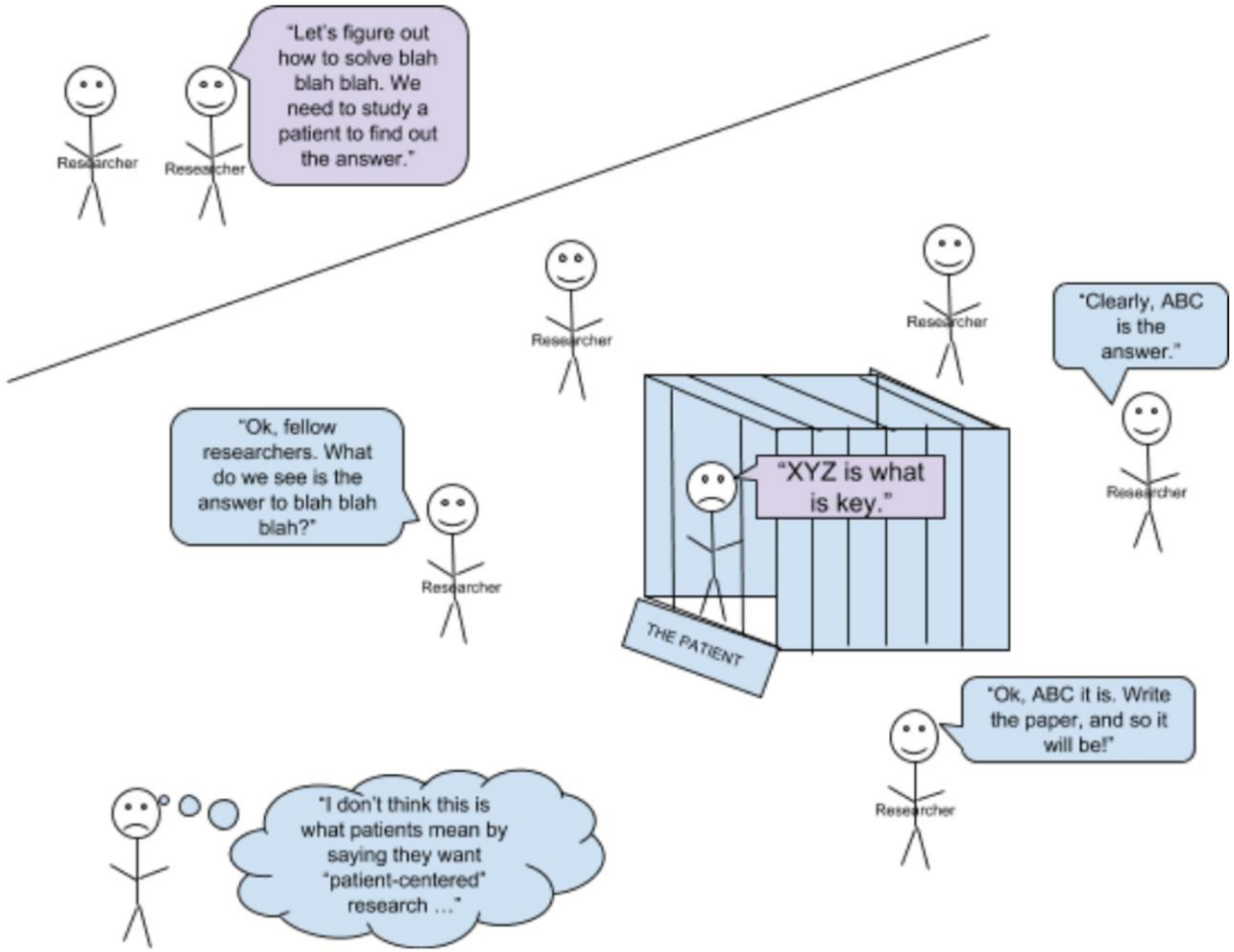
@DanaMLewis

What if the 1% are not exceptions?

Rather, what if they are the undiscovered rule?

@DanaMLewis

RESEARCHERS STUDY A PATIENT:



IN THE FUTURE:

PATIENT: "I am experiencing blah blah blah."

DOCTOR: "The answer is ABC."

PATIENT: "But I think it is XYZ."

DOCTOR: "Well, the research says ABC so ABC it is."

PATIENTS EVERYWHERE: "..."

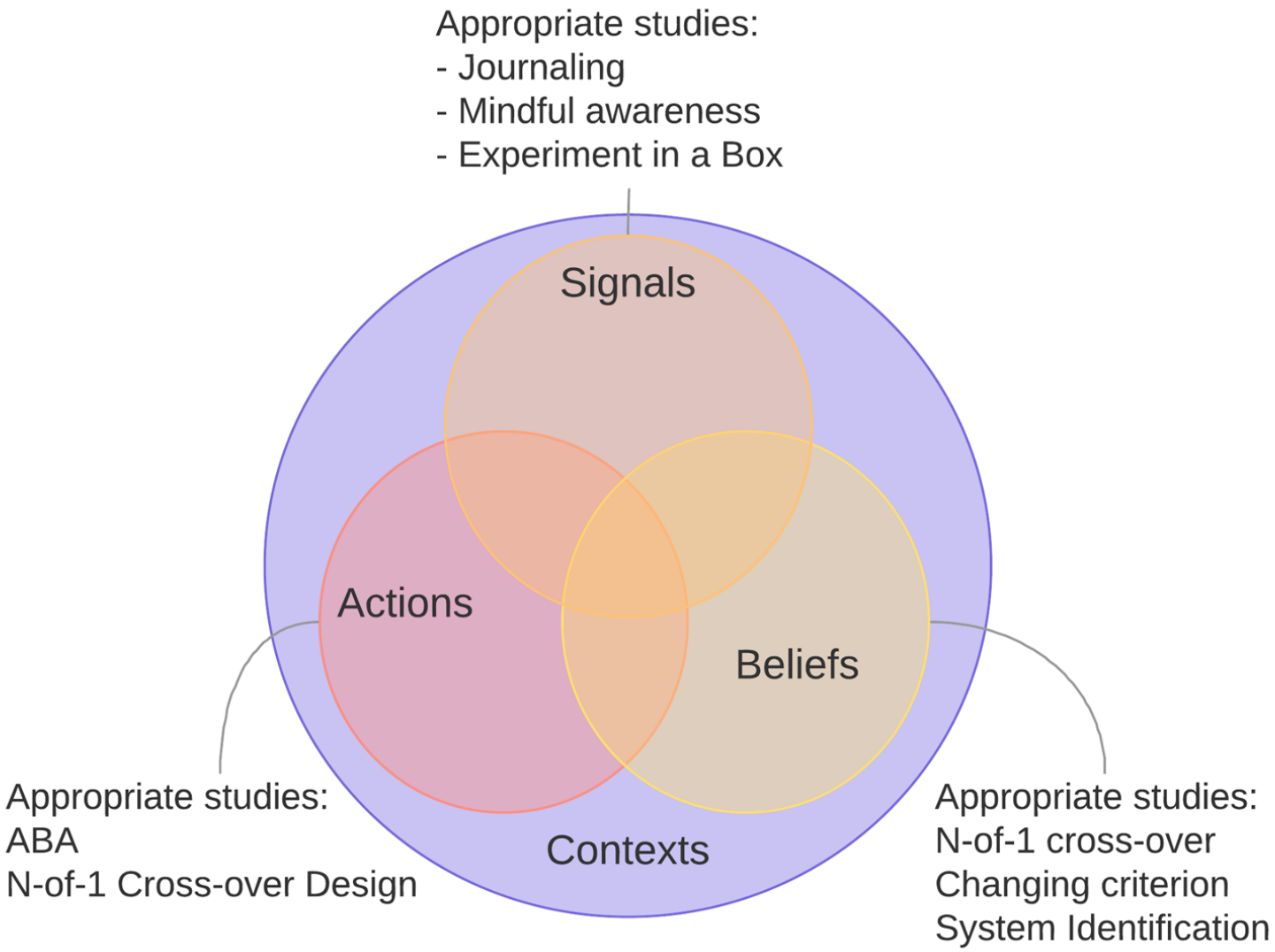
WHEN YOU ONLY TALK THE TALK OF PATIENT-CENTERED RESEARCH

BY @DANAMLEWIS

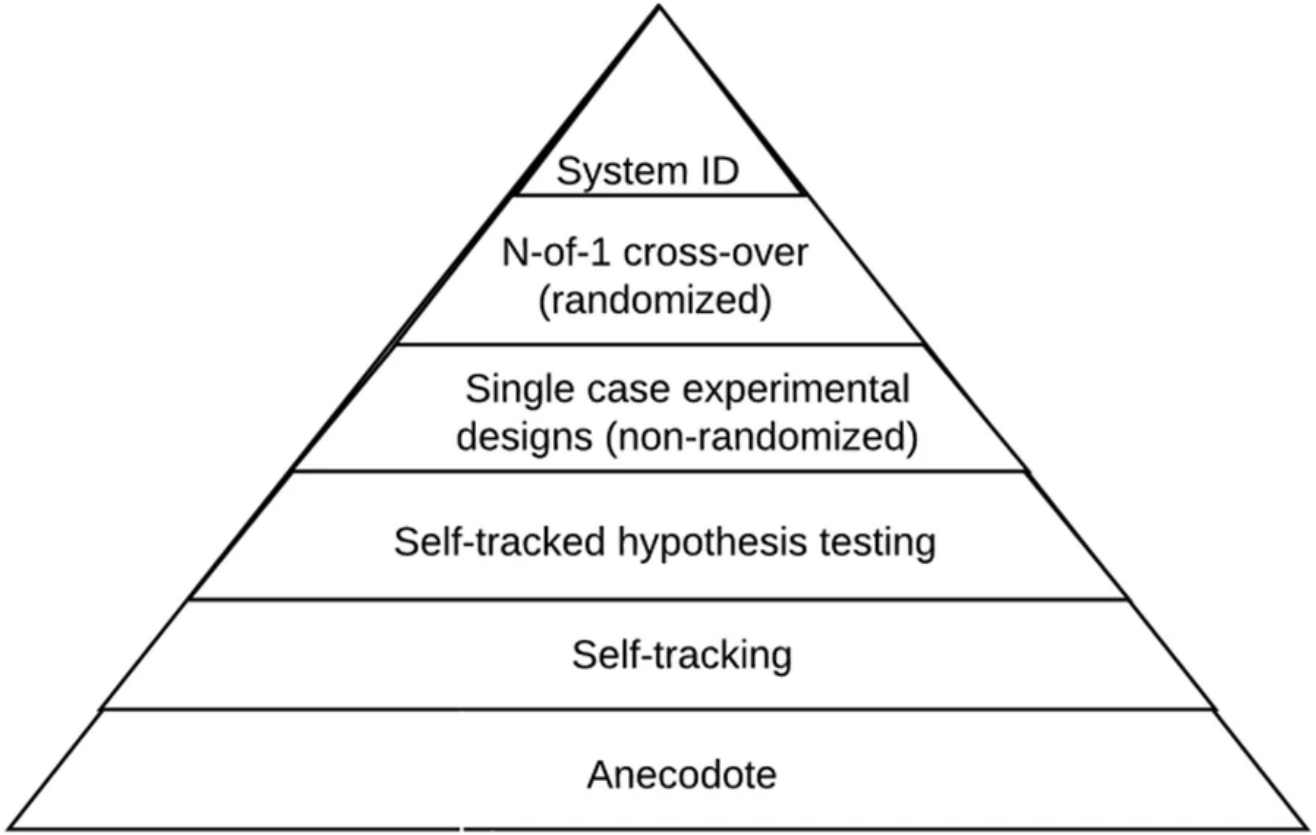
http://openingpathways.org/patient-in-the-cage

2019

- **Define what you want to study**



- **Design and conduct an appropriate study**



https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-019-1366-x/figures/2

Hekler *et al. BMC Medicine* (2019) 17:133
https://doi.org/10.1186/s12916-019-1366-x

BMC Medicine

Beyond Big Data to new Biomedical and Health Data Science: moving to next century precision health

DEBATE Open Access

Why we need a small data paradigm

Eric B. Hekler[1*], Predrag Klasnja[2], Guillaume Chevance[1], Natalie M. Golaszewski[1], Dana Lewis[3] and Ida Sim[4]

Abstract

Background: There is great interest in and excitement about the concept of personalized or precision medicine and, in particular, advancing this vision via various 'big data' efforts. While these methods are necessary, they are insufficient to achieve the full personalized medicine promise. A rigorous, complementary 'small data' paradigm that can function both autonomously from and in collaboration with big data is also needed. By 'small data' we build on Estrin's formulation and refer to the rigorous use of data by and for a specific N-of-1 unit (i.e., a single person, clinic, hospital, healthcare system, community, city, etc.) to facilitate improved individual-level description, prediction and, ultimately, control for that specific unit.

Problem

PNAS

Lack of group-to-individual generalizability is a threat to human subjects research

Aaron J. Fisher[a,1], John D. Medaglia[b,c], and Bertus F. Jeronimus[d]

[a]Department of Psychology, University of California, Berkeley, CA 94720; [b]Department of Psychology, Drexel University, Philadelphia, PA 19104; [c]Department of Neurology, University of Pennsylvania, Philadelphia, PA 19104; and [d]Department of Developmental Psychology, Faculty of Behavioural and Social Sciences, Groningen University, 9712 TS Groningen, The Netherlands

Significance

The current study quantified the degree to which group data are able to describe individual participants. We utilized intensive repeated-measures data—data that have been collected many times, across many individuals—to compare the distributions of bivariate correlations calculated within subjects vs. those calculated between subjects. Because the vast majority of social and medical science research aggregates across subjects, we aimed to assess how closely such aggregations reflect their constituent individuals. We provide evidence that conclusions drawn from aggregated data may be worryingly imprecise. Specifically, the variance in individuals is up to four times larger than in groups. These data call for a focus on idiography and open science that may substantially alter best-practice guidelines in the medical and behavioral sciences.

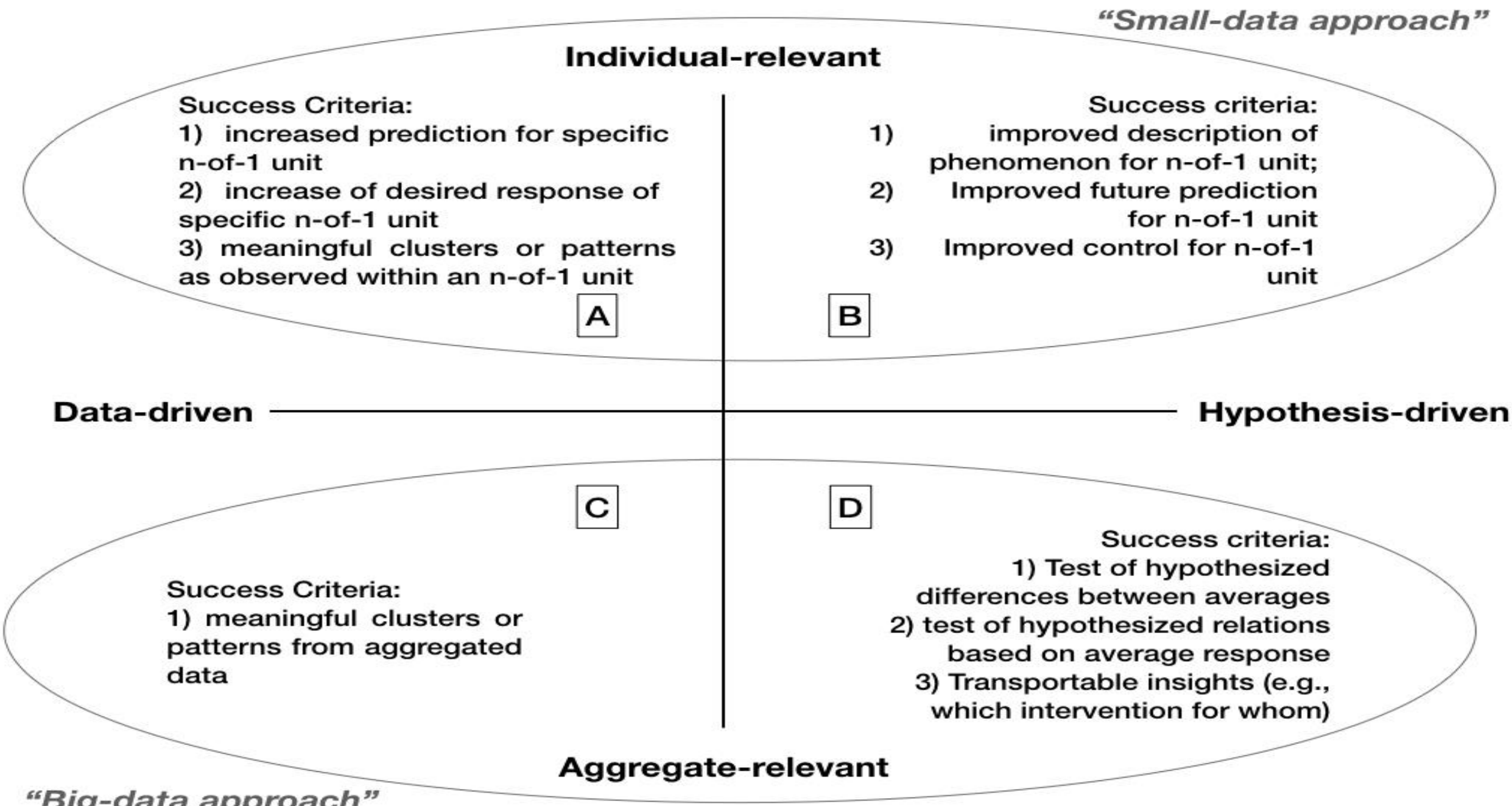
Big vs. small data

Big Data

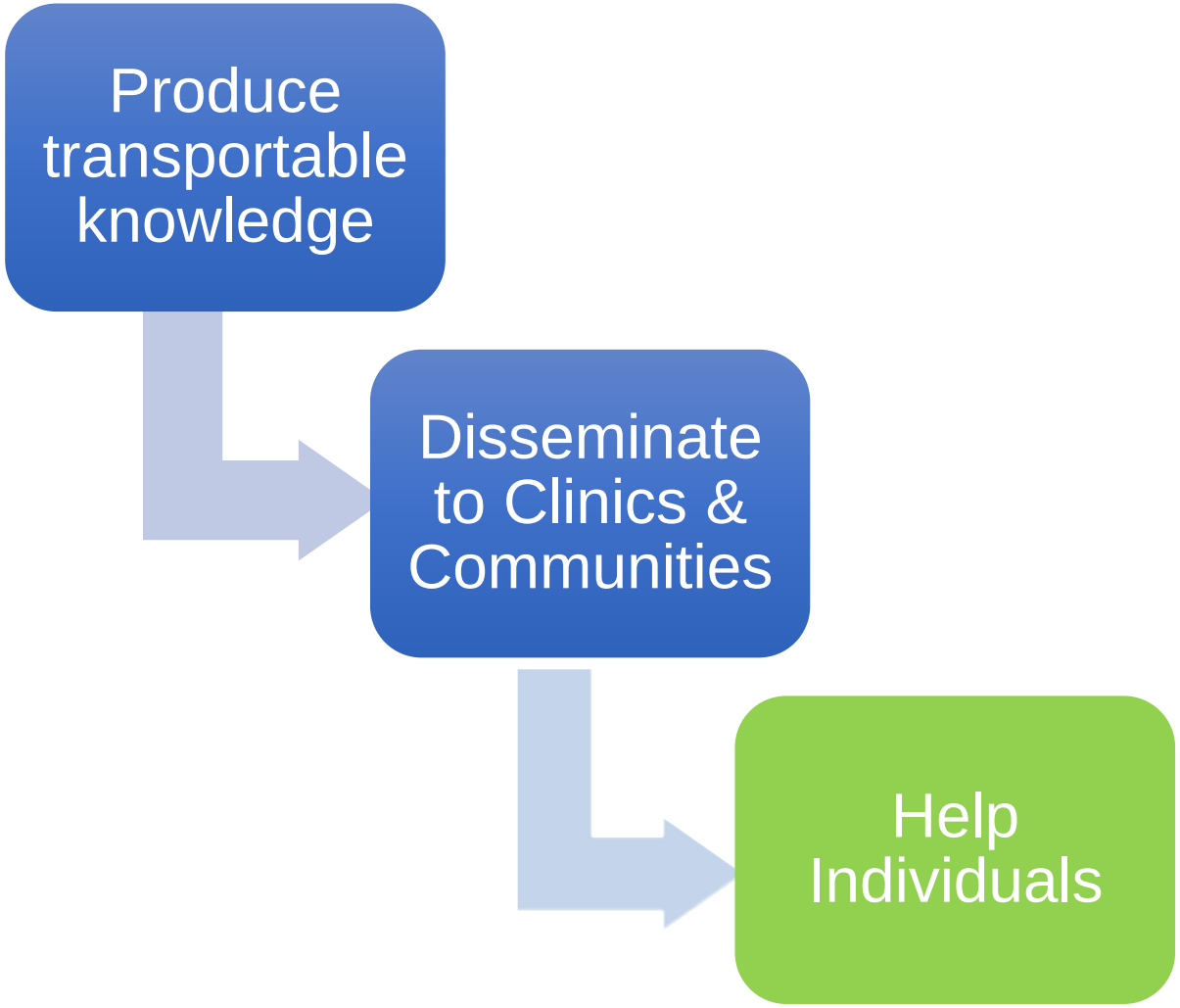
- Data used to help others, not the individual providing the data
- N=many (focus across individuals)
- Researcher-led, aligned to "on average" knowledge
- Improves the "warm start"

Small Data

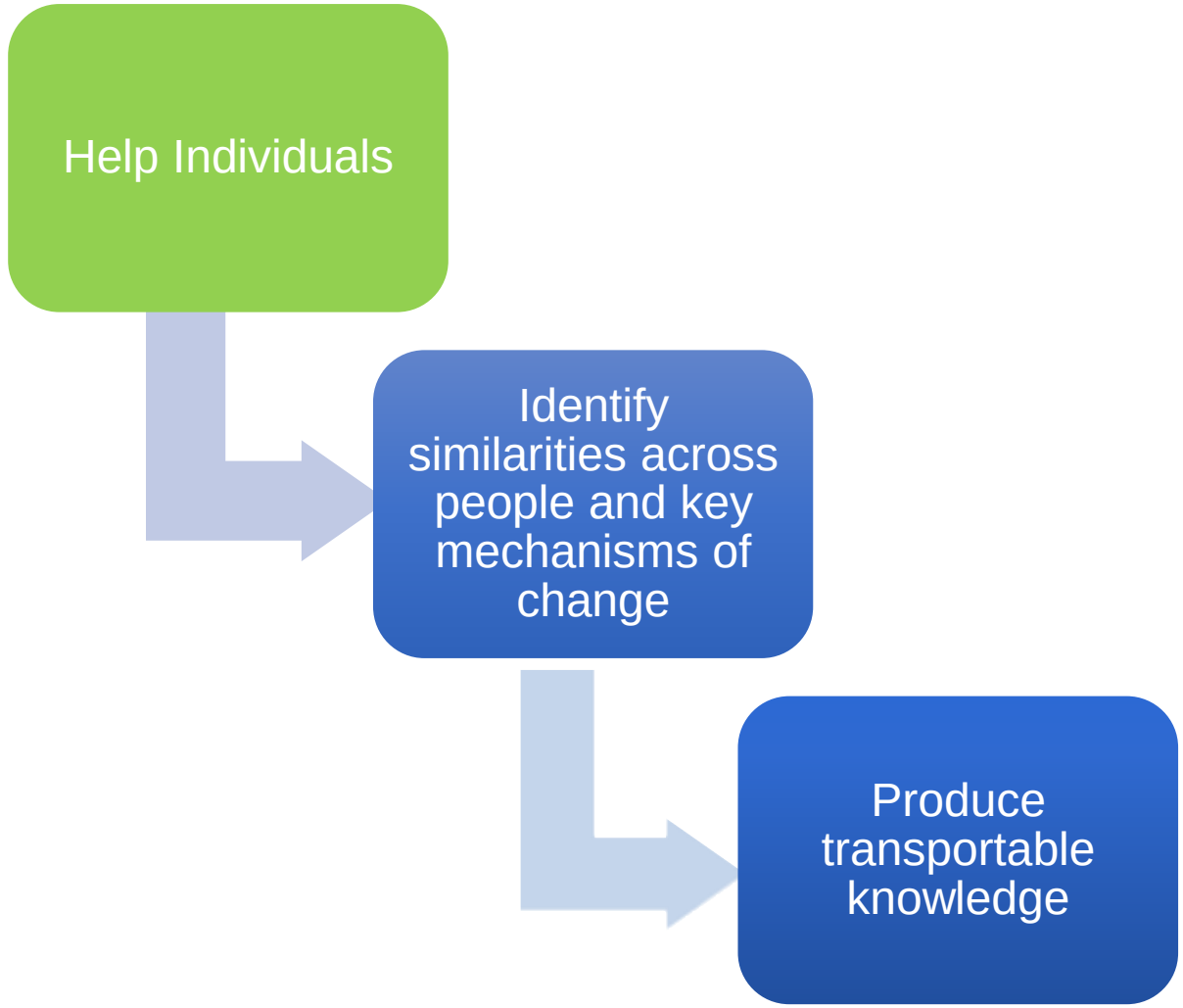
- Data used to help the individual for whom the data are about
- N=1 (focus across time)
- Individual-<>co-<>researcher, aligned to individual's success
- Goes beyond the warm start


"Small-data approach"
Individual-relevant
Success Criteria:
1) increased prediction for specific n-of-1 unit
2) increase of desired response of specific n-of-1 unit
3) meaningful clusters or patterns as observed within an n-of-1 unit
A
Success criteria:
1) improved description of phenomenon for n-of-1 unit;
2) Improved future prediction for n-of-1 unit
3) Improved control for n-of-1 unit
B
Data-driven
Hypothesis-driven
C
Success Criteria:
1) meaningful clusters or patterns from aggregated data
D
Success criteria:
1) Test of hypothesized differences between averages
2) test of hypothesized relations based on average response
3) Transportable insights (e.g., which intervention for whom)
Aggregate-relevant
"Big-data approach"

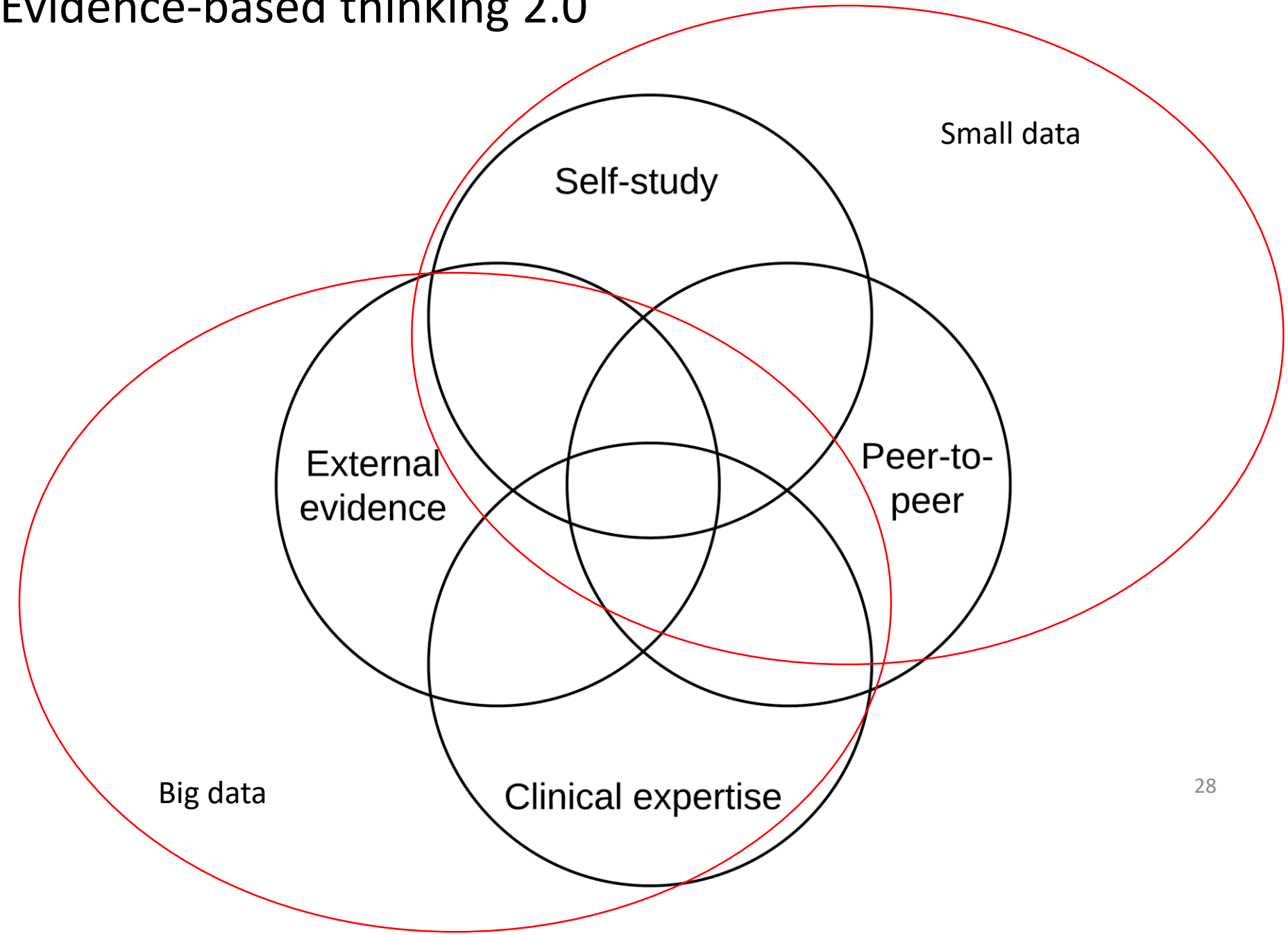
Big Data Paradigm



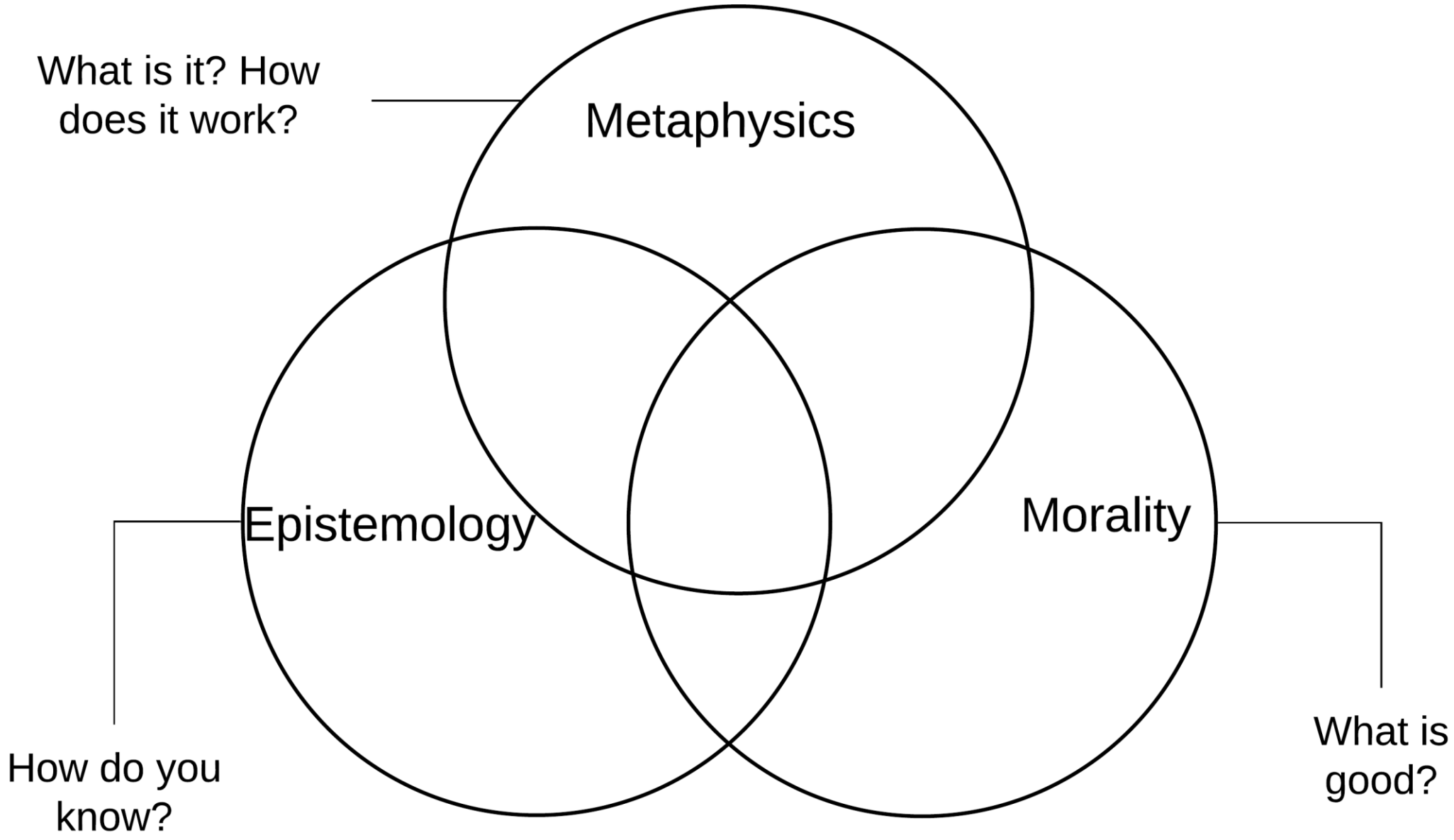
Small Data Paradigm



Evidence-based thinking 2.0



Taking a philosophical stance



	Medicine	Sports Science
“Metaphysics”	Diagnostics and interventions can be used to treat and prevent diseases.	The body is the enabler of adaptive performance of humans in context.

	Medicine	**Sports Science**
"Metaphysics"	Diagnostics and interventions can be used to treat and prevent diseases.	The body is the enabler of adaptive performance of humans in context.
Epistemology	•Learn from or conduct "basic science" to understand the systems in the body (e.g., immune, endocrine, cardiovascular, nervous etc) towards identification of abnormal function. •Develop diagnostics and interventions to treat or prevent physical diseases. •Conduct clinical trials, particularly RCTs, to evaluate if it works. •Implement diagnostics and interventions that "work" into the real-world (e.g. hospitals, self-care).	•Learn from or conduct "basic science" of the body to understand adaptation of the body in context (e.g., motor learning, exercise physiology, nutrition, neurology) •Translate insights into actionable measures and interventions to improve adaptive performance •Engage in rigorous measurement and training to support desired performance adaptation for an individual in context •Cultivate skills, practices, and performances of individuals to achieve desired performance

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Morality (Short-term success criteria)	A disease is cured or prevented, or managed if not curable.	A person's body achieves measurable performance improvements in context against personal reference.

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Morality (Short-term success criteria)	A disease is cured, or prevented or managed if not curable.	A person's body achieves measurable performance improvements in context against personal reference.
Long-term success criteria	There are cures to all diseases.	All people adaptively perform to their genetic potential towards desired states.

Dimensions of citizen to everyday science

Who is in charge?

- Professional-led
  - FoldIt
- Co-developed
  - Opening Pathways to Innovation
  - MakerNurse
- Participant-led
  - OpenAPS
  - Article 27/Everyday Science
  - Self-study

Who does it help?

- Science
  - Propeller Health
  - Spatiotemporal allergic rhinitis symptom monitoring
- Historically marginalized groups
  - L.A.U.N.C.H.
  - OurVoice
- Communities & individuals themselves
  - DIY Geiger Counter
  - Quantified Self
  - Biohackers

What is targeted?

- Diagnostics & treatment
  - Patient-Centered Outcomes Research Initiative (PCORI)
- Prevention
  - Youth-led participatory action research (YPAR)
  - Promotoras
- Enable health
  - Community-based participatory research (CBPR)

@ehekler