For whom and when will we be able to navigate
which aspects of our health through apps
and wearables outside the safe harbours
of medical clinics anywhere on the globe

Inspire2Live Congress
Amsterdam
Nov 29, 2023

4YOUHME

Listening to patterns

Denial

How to avoid being asleep

What we need from each other

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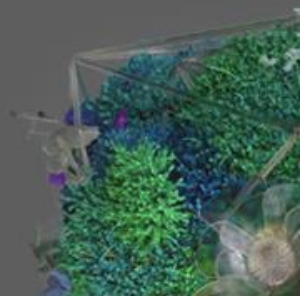


The allure of journeys almost over- links between diseases and genes

Isolation of candidate cDNAs for portions of the Duchenne muscular dystrophy gene

Anthony P. Monaco*†, Rachael L. Neve*†, Chris Colletti-Feener*, Corlee J. Bertelson*, David M. Kurnit* & Louis M. Kunkel*†‡

* Division of Genetics, Mental Retardation Program, Department of Pediatrics, Harvard Medical School, The Children's Hospital, Boston, Massachusetts 02115, USA
† The Program in Neuroscience, Harvard University, Cambridge, Massachusetts 02138, USA

Duchenne muscular dystrophy (DMD) and the less severe Becker muscular dystrophy (BMD) are human X-linked muscle-wasting disorders that have been localized to the band Xp21 by genetic linkage analysis[1–9] and cytologically detectable abnormalities[10–12]. A cloned DNA segment, DXS164 (or pERT87), has been shown to detect deletions in the DNA of unrelated DMD and BMD males[13–15]. Here we present the nucleotide sequence of two highly conserved DNA fragments from the DXS164 locus and their homologous sequences from the mouse X chromosome. One of the human conserved segments hybridized to a large transcript in RNA isolated from human fetal skeletal muscle and was used to isolate cDNA clones which cover approximately 10% of this transcript. The cDNA clones map to Xp21 and hybridize with a minimum of eight small regions that span 130 kilobases (kb) of the DXS164 locus. These expressed sequences are candidates for portions of the gene responsible for both DMD and BMD.

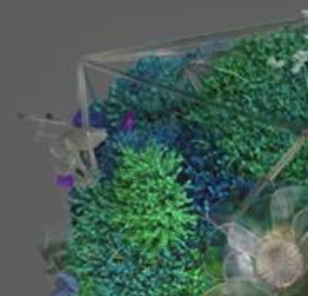
A human DNA segment with properties of the gene that predisposes to retinoblastoma and osteosarcoma

Stephen H. Friend*†, Rene Bernards*, Snezna Rogelj*, Robert A. Weinberg*‡, Joyce M. Rapaport§, Daniel M. Albert§ & Thaddeus P. Dryja§

* Whitehead Institute for Biomedical Research, Cambridge, Massachusetts 02142, USA
† Division of Hematology-Oncology, The Children's Hospital, Dana-Farber Cancer Institute, Department of Pediatrics, Harvard Medical School, Boston, Massachusetts 02115, USA
‡ Department of Biology, Massachusetts Institute of Technology, Cambridge, Massachusetts 02139, USA
§ Department of Ophthalmology, Harvard Medical School and Massachusetts Eye and Ear Infirmary, 243 Charles Street, Boston, Massachusetts 02114, USA

The genomes of various tumour cells contain mutant oncogenes that act dominantly, in that their effects can be observed when they are introduced into non-malignant cells[1–4]. There is evidence for another class of oncogenes, in which tumour-predisposing mutations are recessive to wild-type alleles[5–7]. Retinoblastoma is a prototype biological model for the study of such recessive

Mid 1980s- sense of cracking wide open the disease puzzles- but



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power to predict but not power to treat

Synthetic Lethal Screens to selectively kill tumor cells

CLINICAL IMPLICATIONS OF BASIC RESEARCH

Emerging Uses for Genomic Information in Drug Discovery

Stephen H. Friend, M.D., Ph.D., and Allen Oliff, M.D.

Article Figures/Media

January 8, 1998
N Engl J Med 1998; 338:125-126
DOI: 10.1056/NEJM199801083380211

8 References 19 Citing Articles

GENETICISTS WHO STUDY YEAST, WORMS, AND FRUIT FLIES HAVE LONG recognized that an effective way to identify genes with functional relevance to a particular biologic process is to screen large numbers of mutagenized organisms. Researchers have recently used these primitive organisms to pinpoint genetic mechanisms in human diseases. This approach has succeeded mainly because genome-sequencing projects have discovered numerous invertebrate homologues of human genes. The gene involved in basal-cell carcinoma, for example, was cloned in part through its similarity to the *patched* gene of the fruit fly *Drosophila melanogaster*. [1,2]

New work on two breast-cancer–susceptibility genes, *BRCA1* and *BRCA2*, is a superb example of how information gained from primal organisms can point to the molecular

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SageBionetworks

A research commons enabling secondary research

promote an ecosystem where
research is conducted
for others to consume

SCIENTIFIC DATA

Synapse

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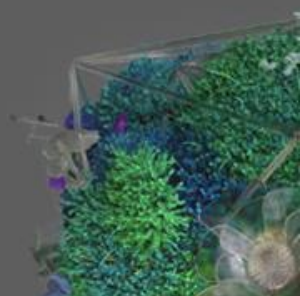

transition to working on wearables

when genotyping was becoming more informative that phenotyping

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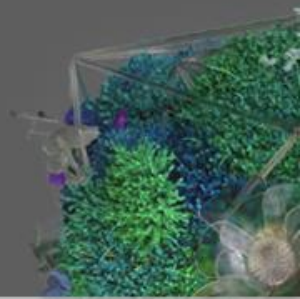

static and somewhat constrained by definitions of symptoms with subjectivity of examining clinicians

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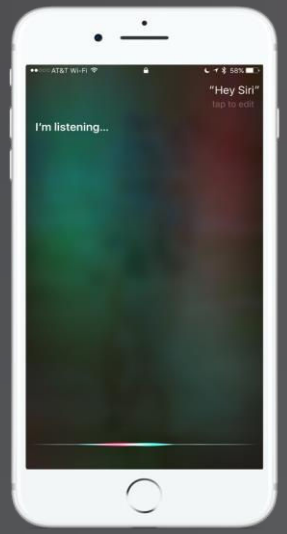
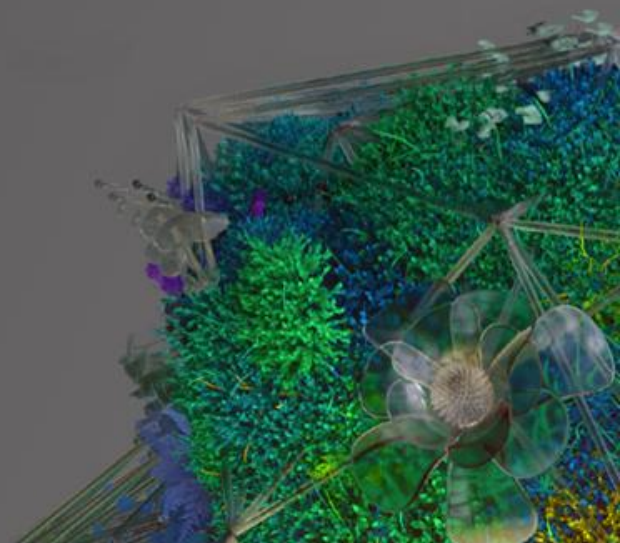
touch hearing sight taste smell





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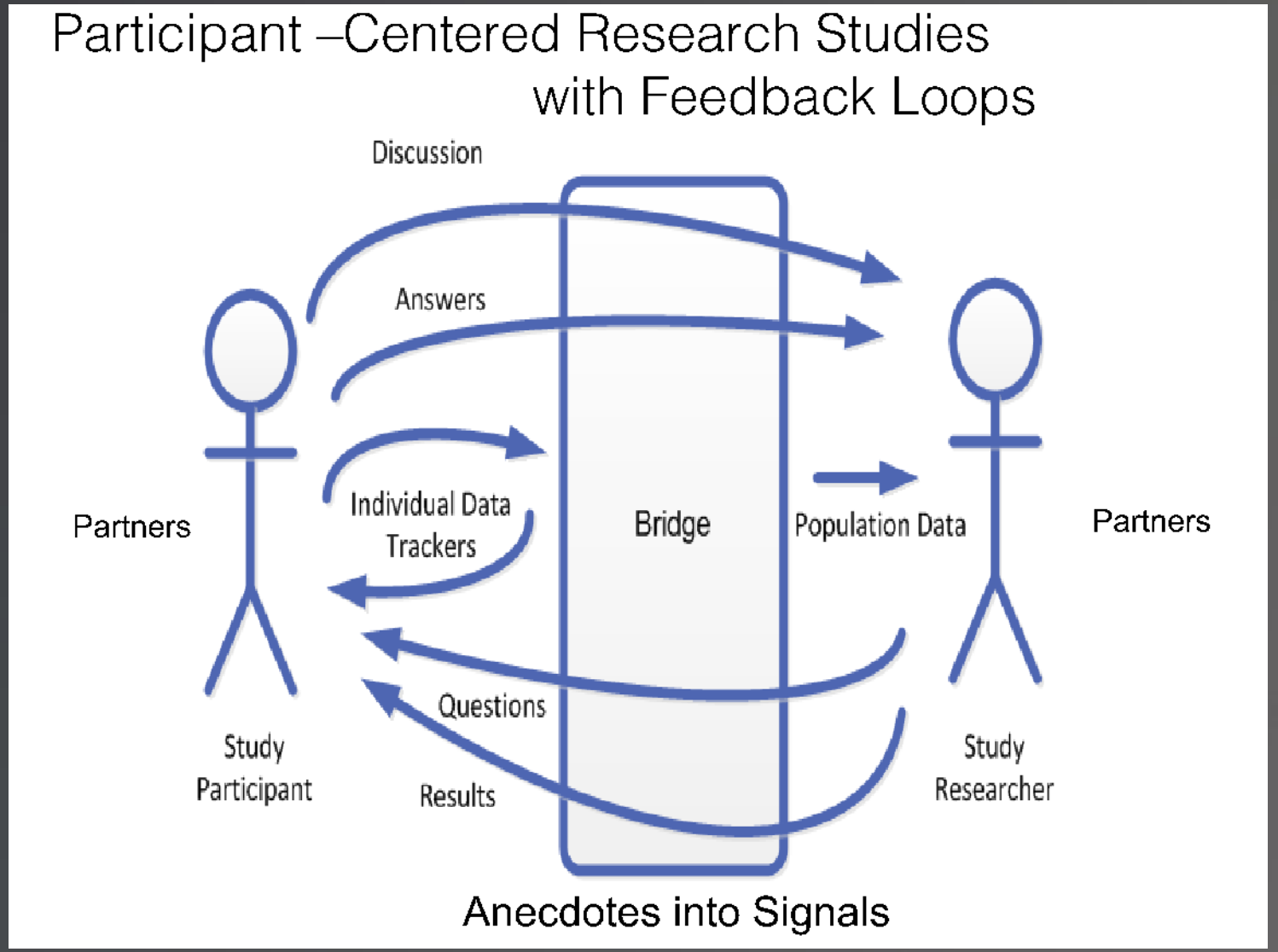

Support
provided by
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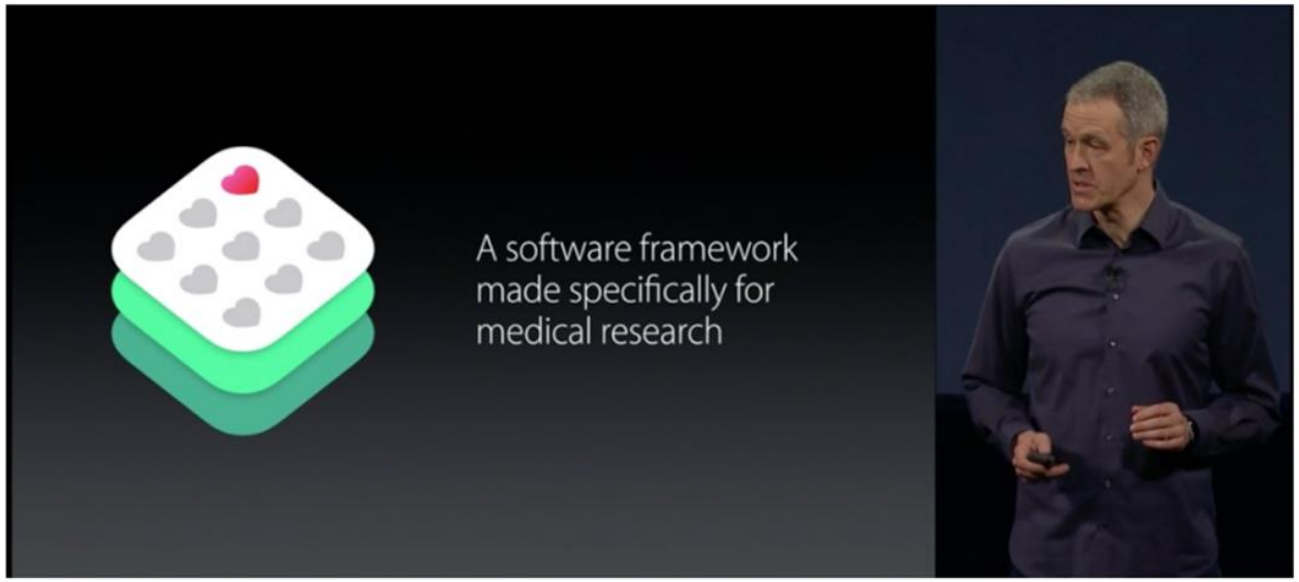
How to exit the medieval framing of participants as “subjects” to be probed and incented to do what others demand of them

TIM MOYNIHAN GEAR 03.09.15 02:05 PM

APPLE'S RESEARCHKIT IS A NEW WAY TO DO MEDICAL RESEARCH

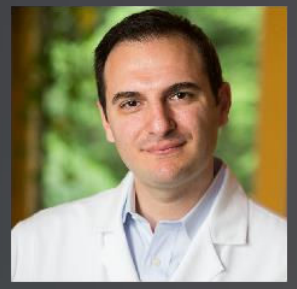


Jeff Williams, senior vice president of operations at Apple, introduces ResearchKit at an event in San Francisco.

SageBionetworks

Dorsey

Trister



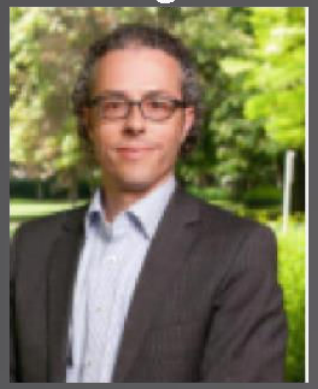
mPower

Klein

Kieburtz

Tanner

Kruger



Bloem

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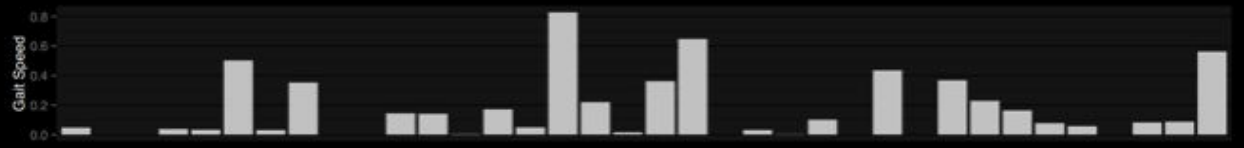
Inter-individual Diversity

no “average humans,” and no single measures for those with Parkinson’s Disease

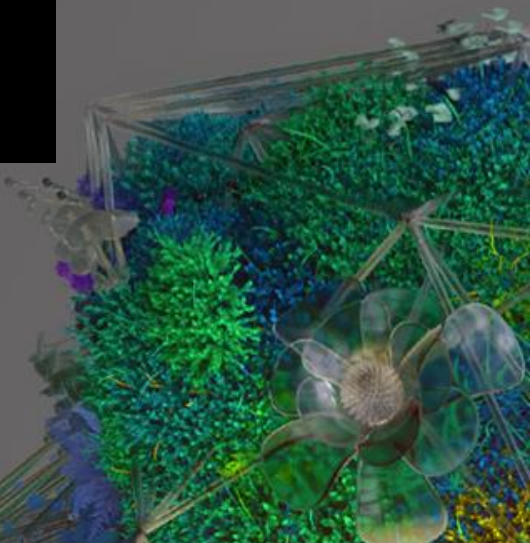
Taps

Gait Speed



Balance

Voice Frequency



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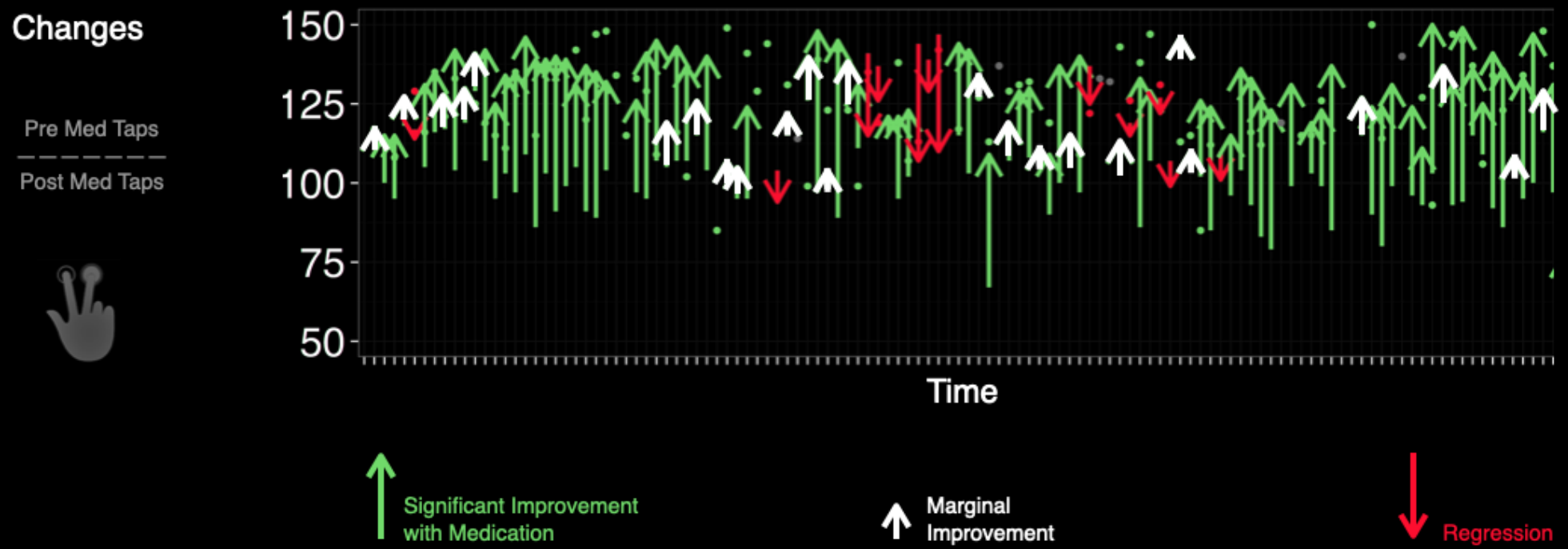
Intra-individual Diversity

among patients with Parkinson's disease



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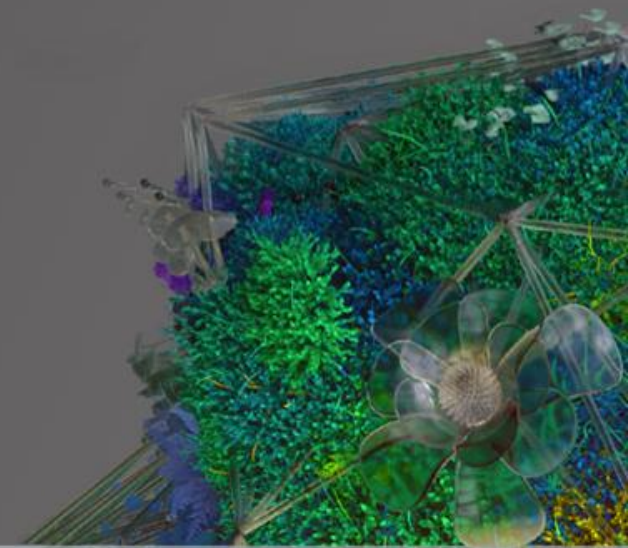
Personal Health Assistant

self-navigate before and after symptoms arise

nurtures actions in times of strength

contributed by each for each other



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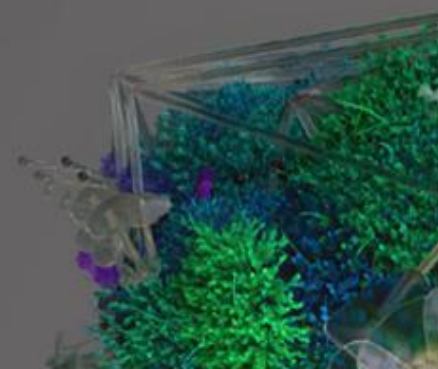
Tackle fundamental unknowns using smart phones and wearables

Enable individual forecasting of symptom transitions

Learn how to effectively return insights to individuals wishing to navigate with health and disease- empower individuals/families

Push on the limits of participant empowered designs and question traditional roles for following diseases and interventions

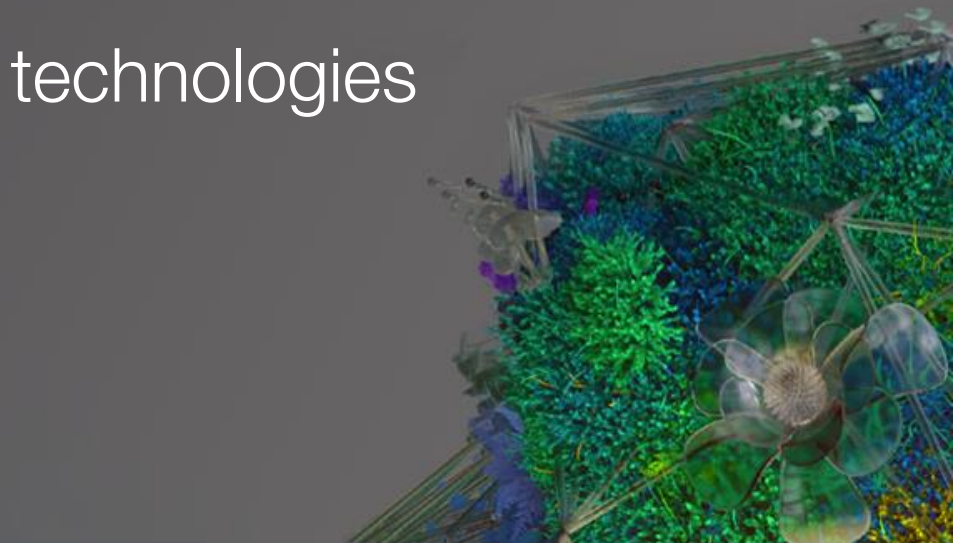
Ensure all data, findings, algorithms, and apps
as possible will be available to all



4YouandMe / Oxford

Ongoing and Completed Studies

using wearables and digital health technologies



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Better Understanding Mechanisms of Pregnancy (BUMP) Study Aims

1. Confirm functionality of integrating digital and clinical data of sufficient quality
2. Identify signals associated with detection and forecasting symptoms
3. Describe inter-individual variation for detecting and forecasting symptoms

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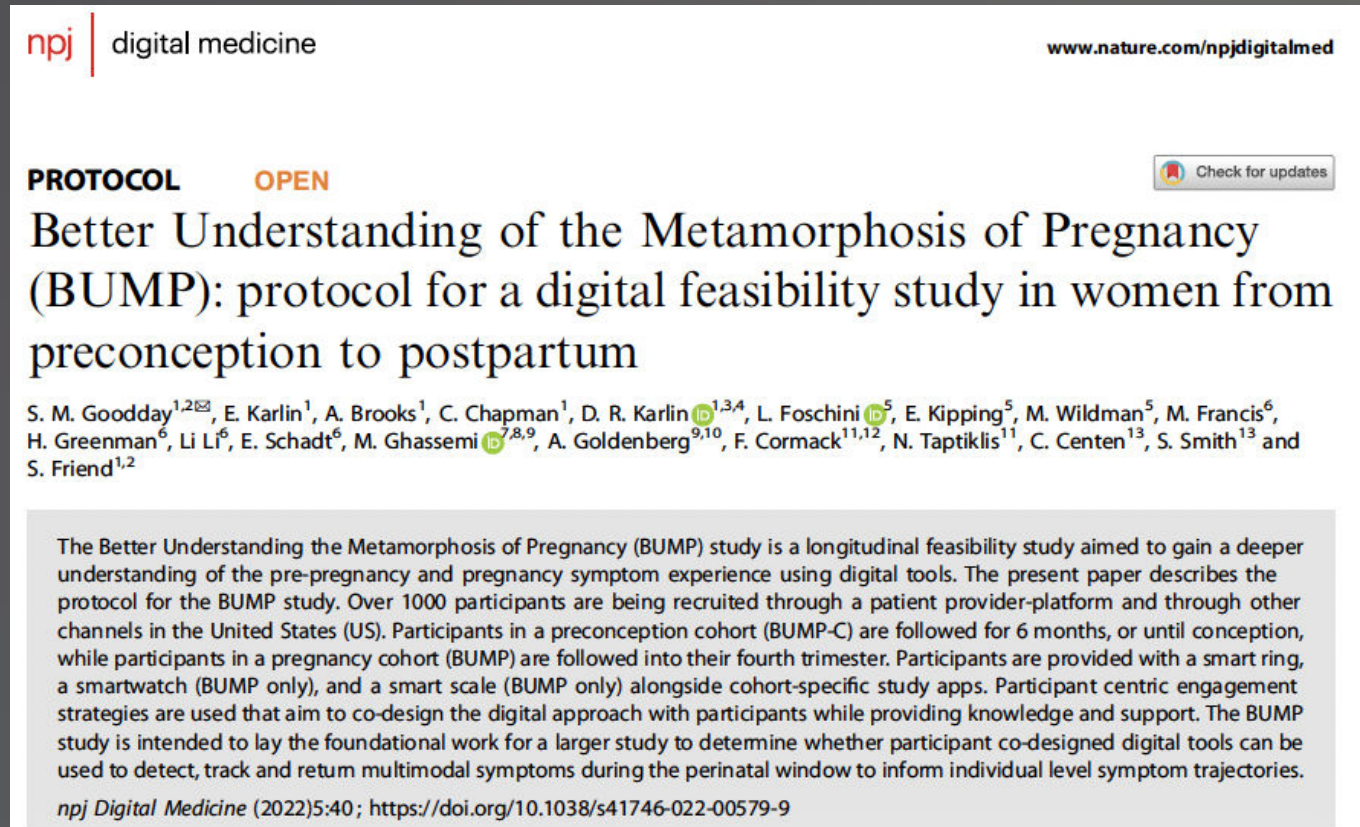

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PROTOCOL OPEN

Check for updates

Better Understanding of the Metamorphosis of Pregnancy (BUMP): protocol for a digital feasibility study in women from preconception to postpartum

S. M. Goodday[1,2✉], E. Karlin[1], A. Brooks[1], C. Chapman[1], D. R. Karlin[1,3,4], L. Foschini[5], E. Kipping[5], M. Wildman[5], M. Francis[6], H. Greenman[6], Li Li[6], E. Schadt[6], M. Ghassemi[7,8,9], A. Goldenberg[9,10], F. Cormack[11,12], N. Taptiklis[11], C. Centen[13], S. Smith[13] and S. Friend[1,2]

The Better Understanding the Metamorphosis of Pregnancy (BUMP) study is a longitudinal feasibility study aimed to gain a deeper understanding of the pre-pregnancy and pregnancy symptom experience using digital tools. The present paper describes the protocol for the BUMP study. Over 1000 participants are being recruited through a patient provider-platform and through other channels in the United States (US). Participants in a preconception cohort (BUMP-C) are followed for 6 months, or until conception, while participants in a pregnancy cohort (BUMP) are followed into their fourth trimester. Participants are provided with a smart ring, a smartwatch (BUMP only), and a smart scale (BUMP only) alongside cohort-specific study apps. Participant centric engagement strategies are used that aim to co-design the digital approach with participants while providing knowledge and support. The BUMP study is intended to lay the foundational work for a larger study to determine whether participant co-designed digital tools can be used to detect, track and return multimodal symptoms during the perinatal window to inform individual level symptom trajectories.

npj Digital Medicine (2022)5:40; https://doi.org/10.1038/s41746-022-00579-9

Equipment Needed

Three wearable devices will be provided to study participants

Fitbit Versa

- 3-axis accelerometer
- 3-axis gyroscope
- Optical heart rate monitor
- Altimeter
- Vibration motor
- WiFi Antennas (802.11 b/g/n)
- 4+ days battery Life

Oura Ring 2

- Heart Rate, Resting Heart Rate (RHR)
- Heart rate variability (HRV)
- Respiration rate, breathing variance
- Sleep stages and quality metrics
- Body temperature variation
- Duration, intensity, and timing of activities
- Inactivity, sedentary time

BodyPort Smart Scale

- Weight
- Pre-ejection Period
- BMI
- Ejection Time
- Impedance
- PEP/LVET
- Peripheral Fluid Content
- Pulse Wave Velocity
- Balance
- Pulse Transit Time
- Pulse Rate
- Pulse Arrival Time
- Heart Rate Variability
- Ejection Force

Fatigue

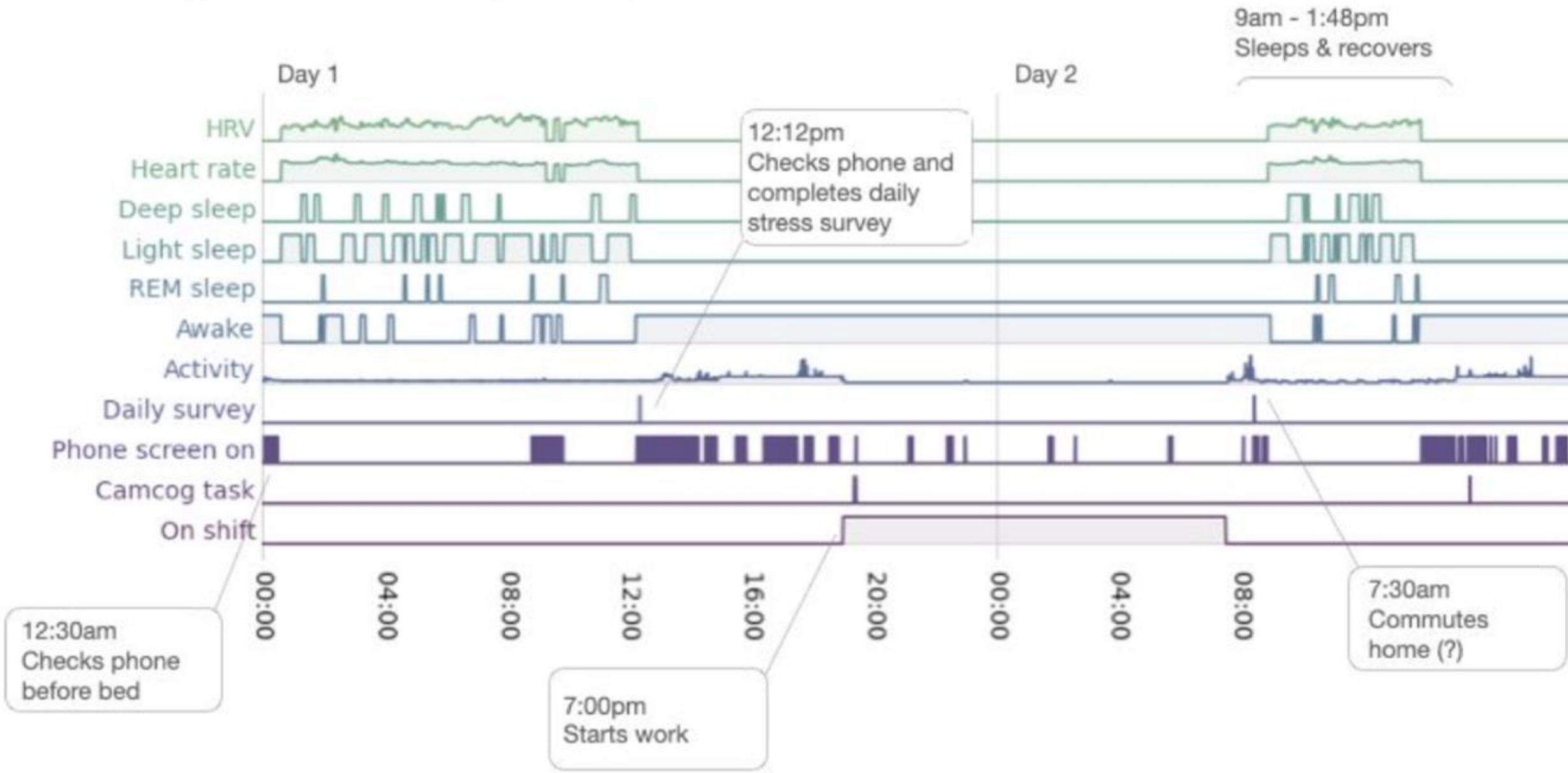
Active

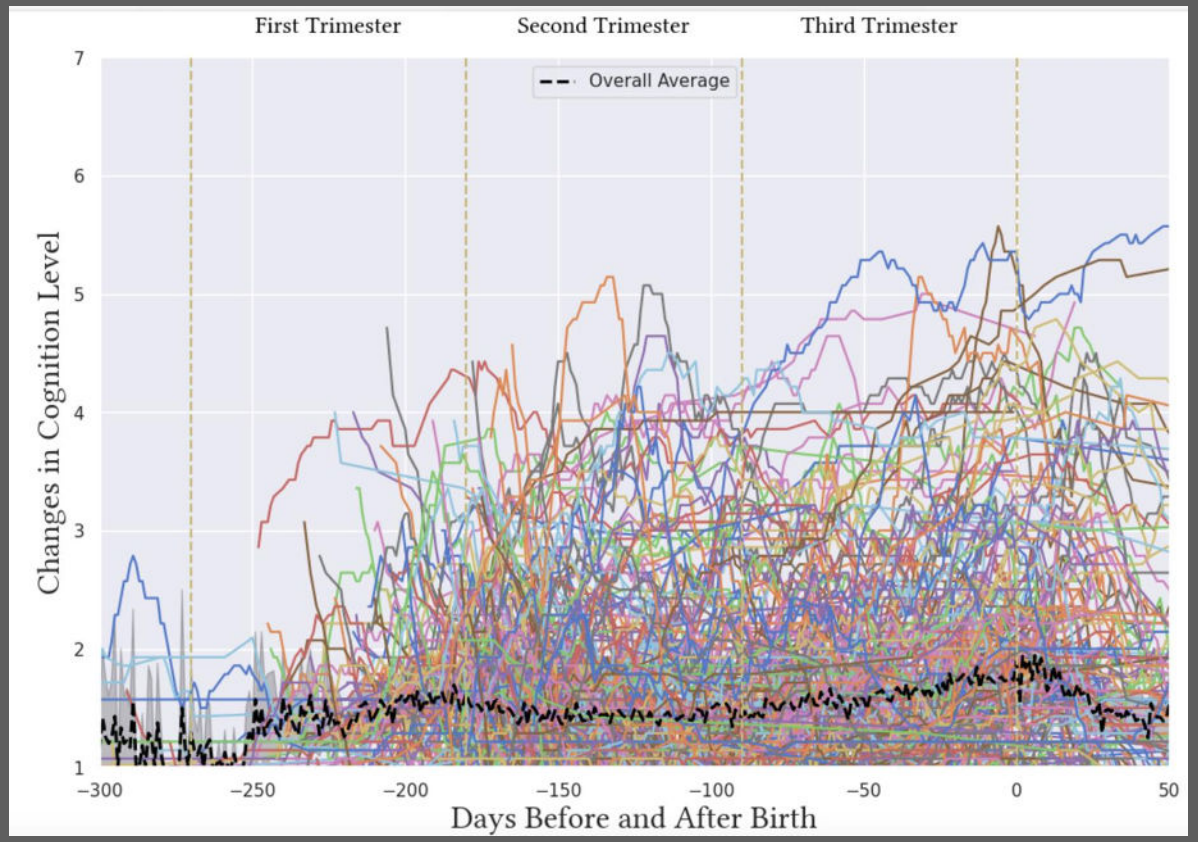
- Study visits
  - Maternal Social Support Index
  - Adverse Childhood Events
  - PHQ-4
  - Perinatal PTSD survey
  - Medical history
  - Birthing data
  - Heart rate
  - Diabetes screens
  - CBC
  - Edinburgh Postnatal Depression Scale
- Camcog
  - N-back task
  - Emotion bias task
  - Psychomotor vigilance test
- In-app
  - Gait task
  - 2-minute walk test
  - Video diary
  - Absolute location (opt-in)
  - SAM EMA
  - Pregnancy symptom survey
  - Medical/pregnancy history survey
  - Quality of life survey
  - Healthcare utilization survey
  - Fatigue survey
  - Emotional support survey
  - Pain interference survey
  - Sleep disturbance survey
  - Sleep related impairment survey
  - Flu / infection question
- Bodyport
  - Left ventricular ejection time

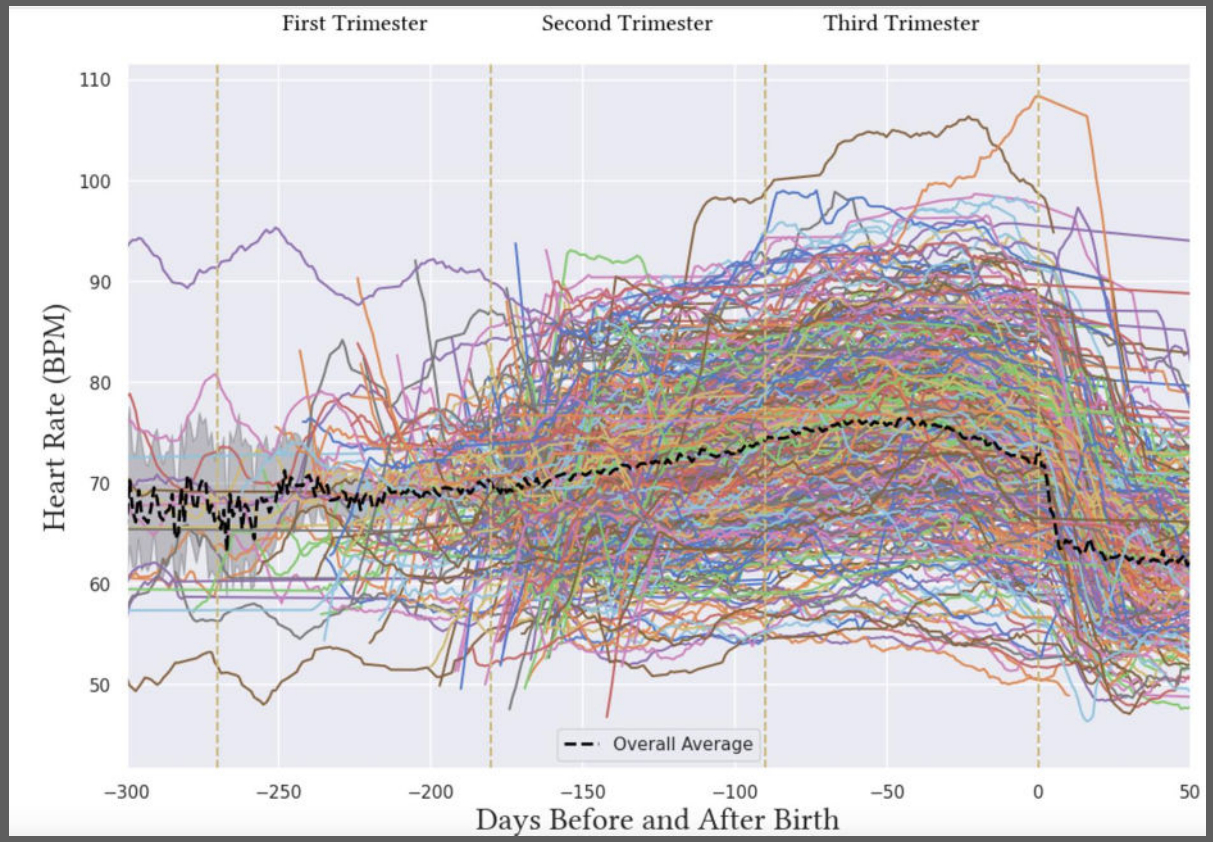
Passive

- Activity
  - Activity score
  - Daily movement
  - Daily steps
  - Metabolic equivalents (1 min)
  - Activity class (5 min)
  - Steps (15 min)
  - Heart rate (1 min)
- Sleep
  - Bedtime start/end delta
  - Heart rate (5 min)
  - Nightly temperature delta
  - Number of sleeps per day
  - Sleep score
  - Circadian alignment
  - Disturbances
  - Sleep levels (5 min)
  - HRV (5 min)
  - Sleep levels
- Readiness score
- Stress level
- Body battery
- Breathing rate (1 min)
- Instagram posts
- Twitter posts & feed
- Phone usage

We process, align and combine data from each source to create a single *behaviorgram* for each participant







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Current and Completed Feasibility Studies

Stress and Recovery: Stress in COVID healthcare workers

BUMP: Forecasting Symptoms of Pregnancy and timing of delivery

Stress in Crohn's: Can stress help forecast flares?

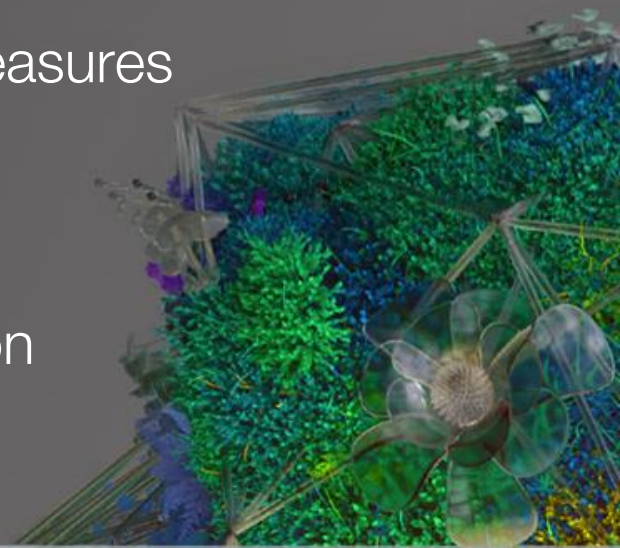
★ HERO: Following the effects of chemo and tumor regrowth

★ HERO: Designing tool to detect early growth of tumors

Diabetes & Stress: How does stress effect continuous glucose measures

Fabric of Life: Effects of Stress on Li-Fraumeni Syndrome

My Experiences: Revamping the Psychiatric system of classification



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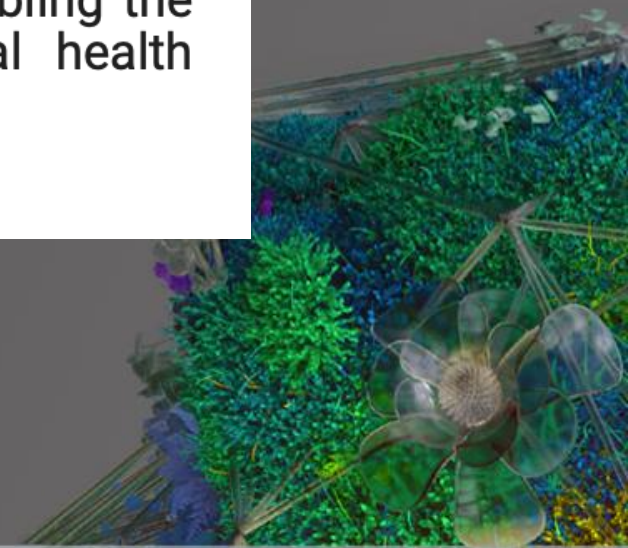
HERO STUDIES

HERO Studies

Helping Enable Real-time Oncology Observations

Feasibility study to determine how using active and passive wearable digital health technology data might track the effects of chemotherapy, adverse effects and tumor growth.

Long-term objective: doing a larger study to design the tools enabling the clinical oncologist to care for patients using wearable digital health technologies.



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HERO STUDIES

Obj 2. How can wearable digital health technologies provide semi-continuous physiologic signs and symptoms of chemotherapy, adverse effects and tumor growth?

Data source	Data subsource	Signal
Study app	Self assessment mannequin	mood
		energy
		stress
		cognition
	Surveys	pilot survey
		basic vitals/demographics
		symptoms (EORTC)
		perceived stress (PSS-4)
		fatigue assessment survey (FAS)
		pain interference (PROMIS)
		sleep related impairment (PROMIS SRI)
		GADS-7
		COVID19

***Table 1.a.** Active signals*

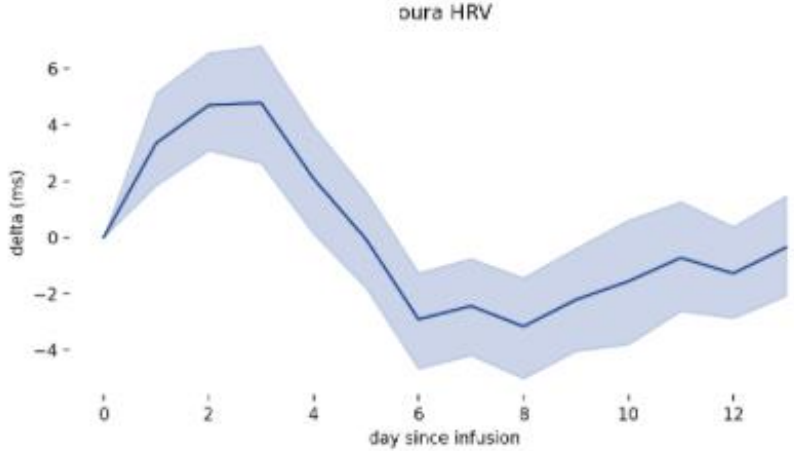
Data source	Data subsource	Signal
Garmin smartwatch	Daily summaries	step count
		distance
		active time
		calories
		resting heart rate
		max heart rate
		stress level
		stress duration
Oura ring	Sleep	bedtime start
		bedtime end
		duration
		heart rate (5 min)
		average heart rate
		lowest heart rate
		heart rate variability (5 min)
		average heart rate variability
		temperature delta
		breathing rate
		sleep score
		readiness score
Bodyport scale	Non-cardiac data	weight
		body impedance
		peripheral fluid
		total body water percentage
	Balance	sway area
		sway velocity

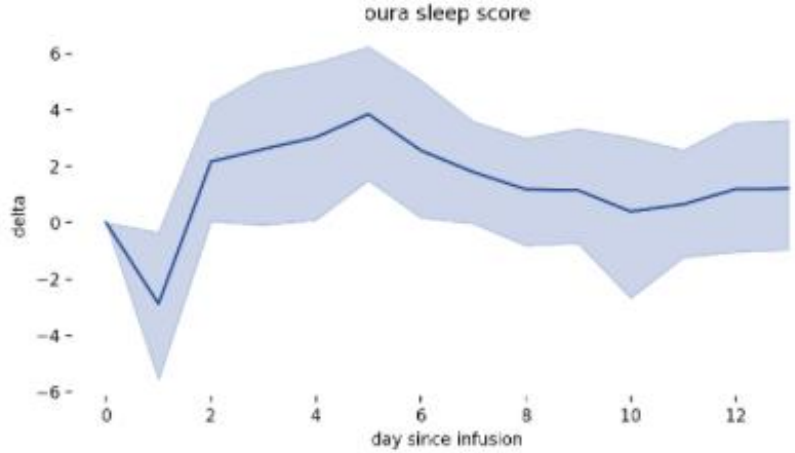
***Table 1.b.** Passive signals*

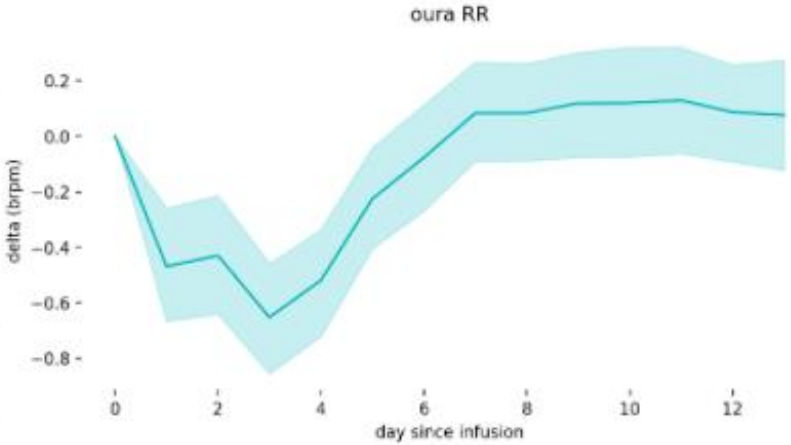
*Note: these lists are **non comprehensive**.*

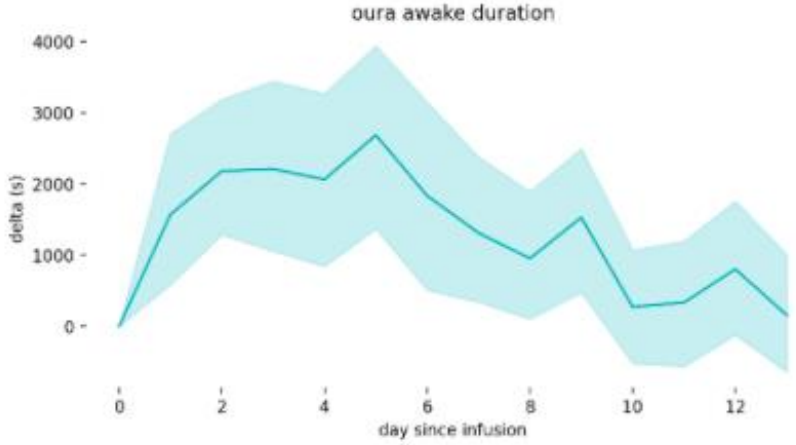
HERO STUDIES

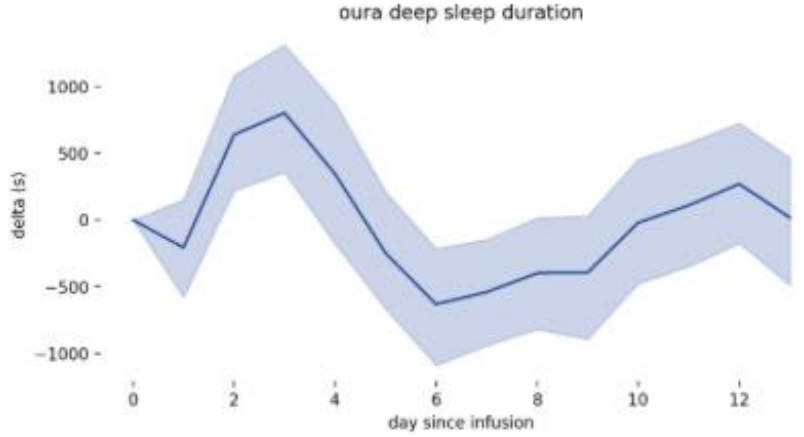
Chemotherapy typical infusion cycles; typical variations across ALL cycles for ALL patients











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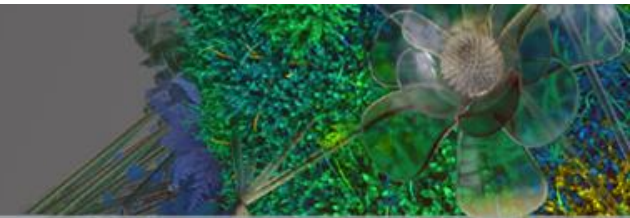


HERO STUDIES- next steps for wearables in Oncology

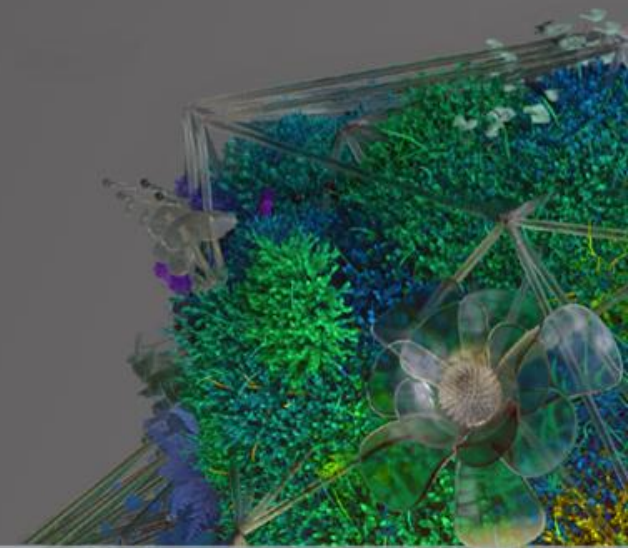
Explore how wearables could be useful in tumor detection

Build dashboard for patients and clinicians to follow effects of cancer therapies and disentangle from adverse effects and question of tumor regrowth

Design way to objectively follow the delivery of “standard” care from center to center across the globe

Improve the ability to follow individuals in clinical trials

Build out alternative to RECIST criteria- “quality of life”



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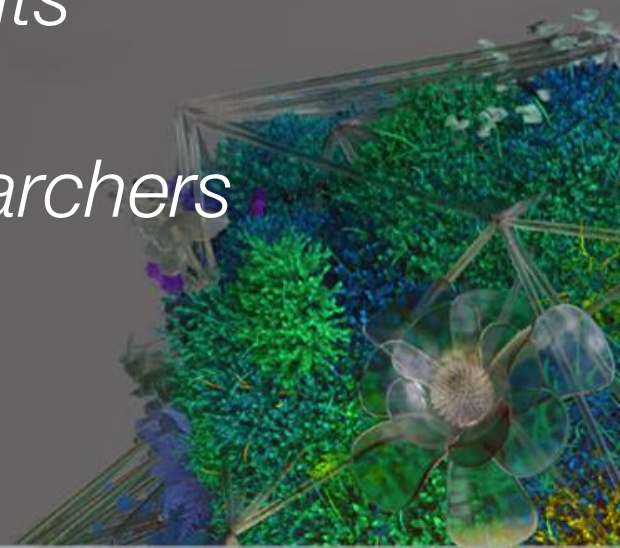
Pushing on the limits of participant driven studies

Co-construct with participants
Co-evolve protocols and consents
Bi-weekly active neutral support calls with all participants
Include ways for participants to follow triggers
Tools to record insights into effects on symptom presentations
Provide scrolling data diaries to follow symptoms
Biweekly participant videos follow feelings and insights
Live forums to share insights and symptoms
Hold ZOOM calls to introduce participants and researchers
Provide opportunities to be co-authors



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Listening to patterns

Denial

How to avoid being asleep

What we need from each other

Healing ourselves

Healing others

Healing the planet

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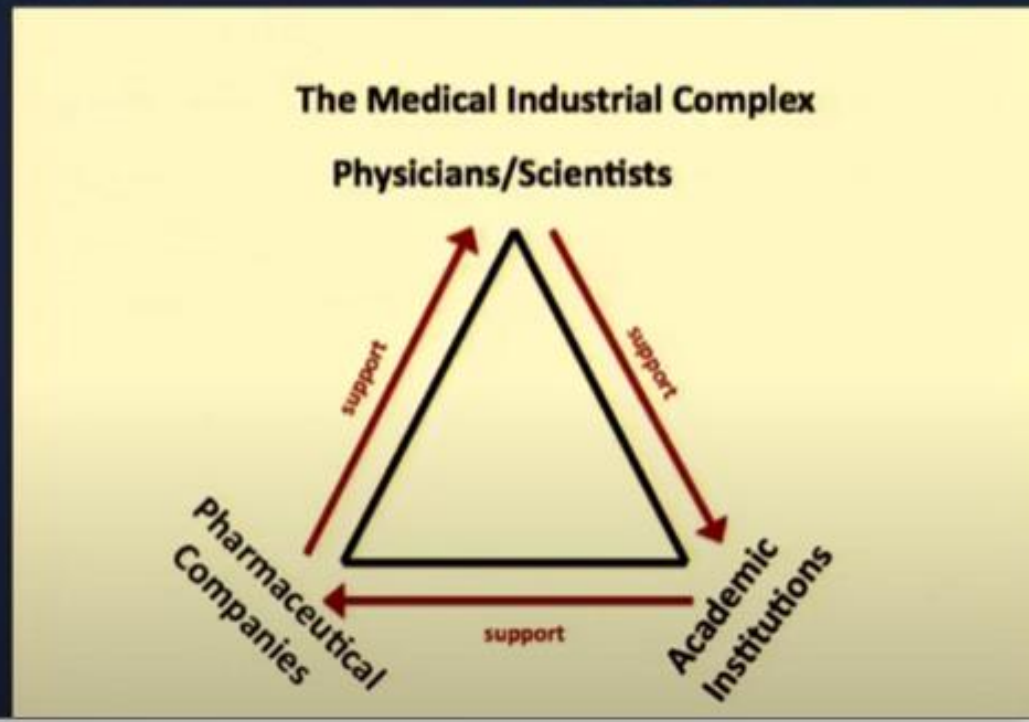
COMMON THEMES TO OBSTACLES

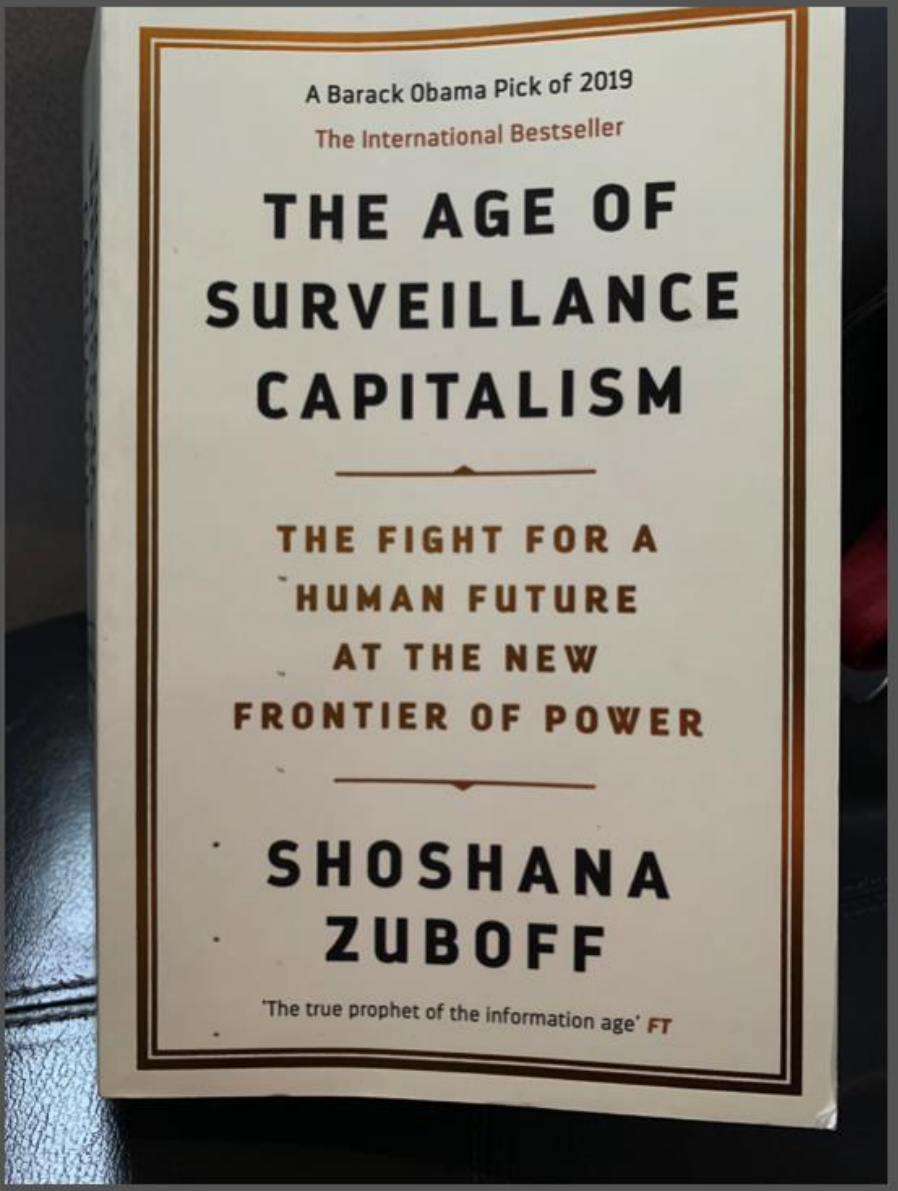
WHY DOES IT GO SO WRONG?

HANNAH ARENDT & SIMONE WEIL

"We Must Guard Against
the acquisition of unwarranted influence,
whether sought or unsought, by the
Military Industrial Complex"
- Dwight D. Eisenhower 1961

5th annual
RECOMB Conference on Regulatory
and Systems Genomics, with DREAM Challenges
San Francisco | November 12-15, 2012





Navigation of Chronic Illnesses in the Age of Surveillance Capitalism

Who will have the data?

Who will have the knowledge?

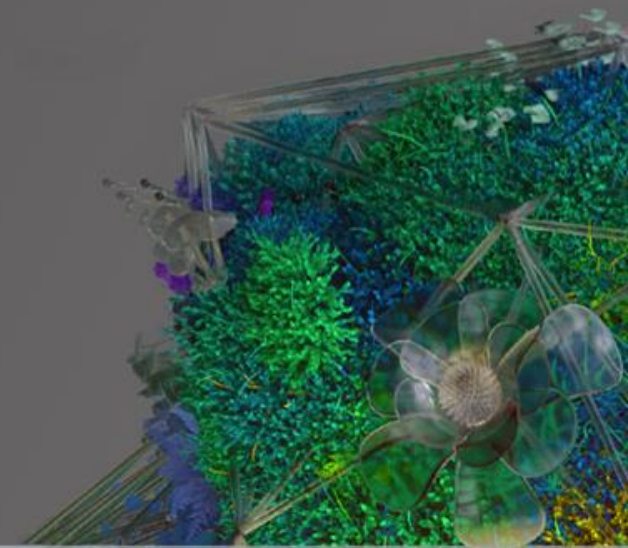
Text

Who will have the power?

How will individuals gain advice?

What will it feel like for others to forecast our future states of health?

We are likely shifting to a world where companies and government's understandings of what we do and how to alter our behaviors will explode because of vast asymmetric knowledge about us.



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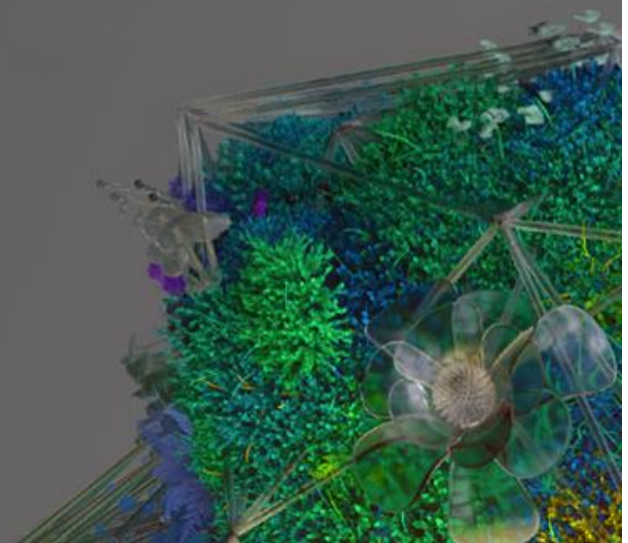
COMMON THEMES- healing self, others and the planet

Who frames the key questions to be solved?

Who decides who sits at the table?

Who sets rewards and incentives?

Who defines “common sense”?



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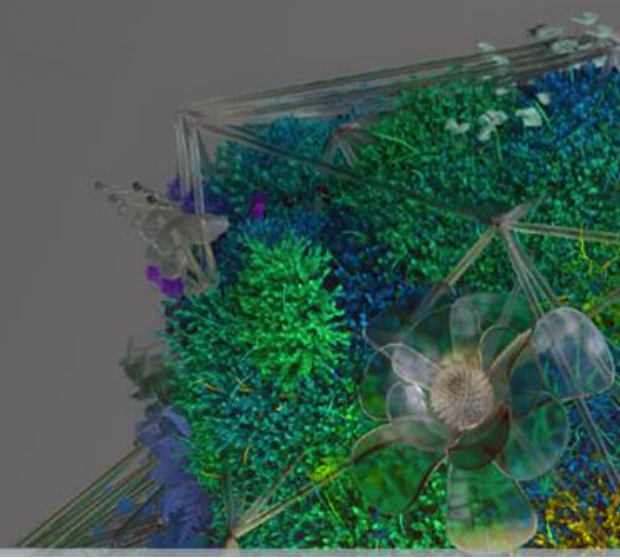
INDIVIDUAL ANXIETY

COLLECTIVE INTELLIGENCE



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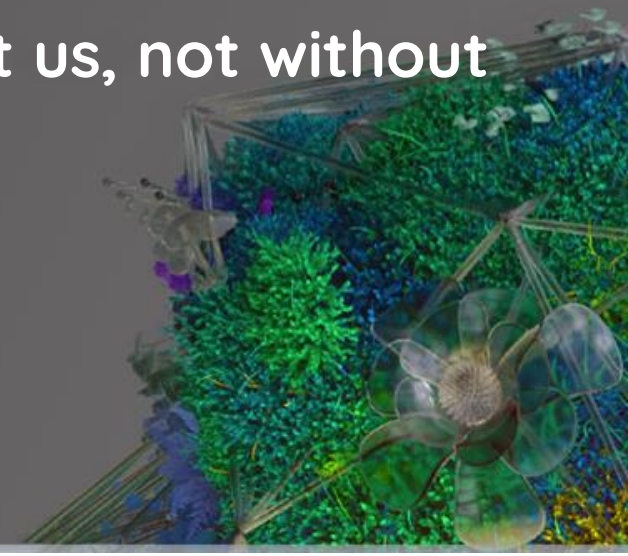
INDIVIDUAL ANXIETY

COLLECTIVE INTELLIGENCE

We have to be at the table to bring in our voice: **‘If about us, not without us.’**



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INDIVIDUAL ANXIETY

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LEARNING PLANET INSTITUTE

PLANETIZEN UNIVERSITY

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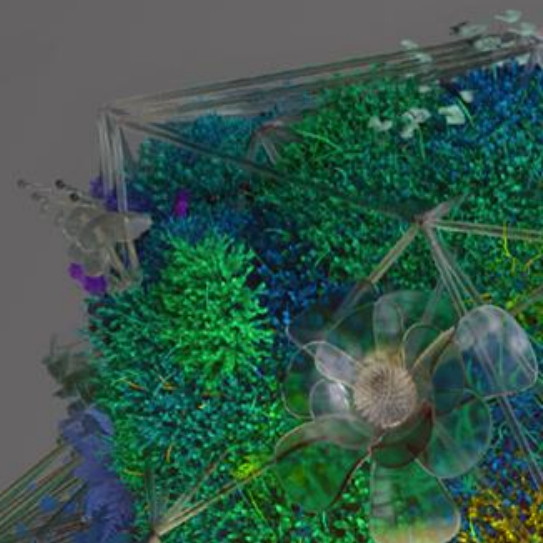

Listening to patterns

Denial

How to avoid being asleep

What we need from each other

“work on specific problems - but look for overriding common obstacles”

“forgive us for we know not”

“we are flawed- and we are possibly more risky than AI”

“dangers when evolving insights faster than we can understand “

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