Small data and patient-driven health applications

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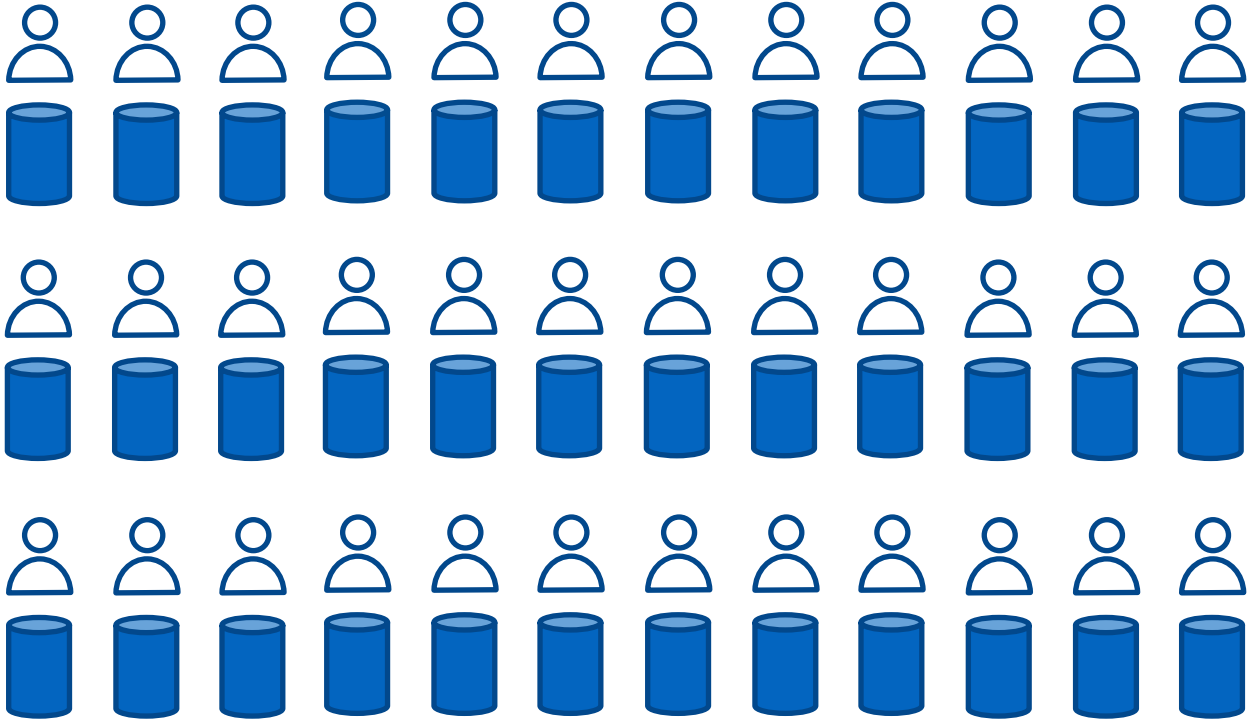
Curiosity Health

Part 1: Small data & data collection

What is small data?



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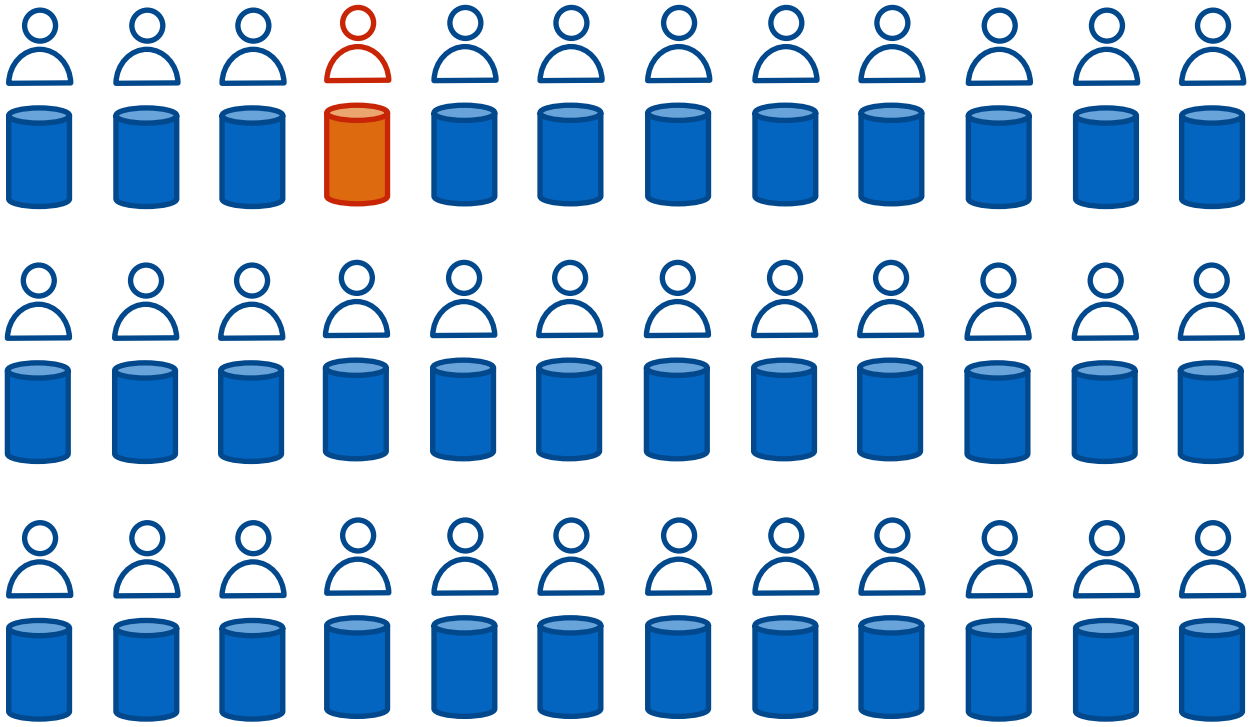

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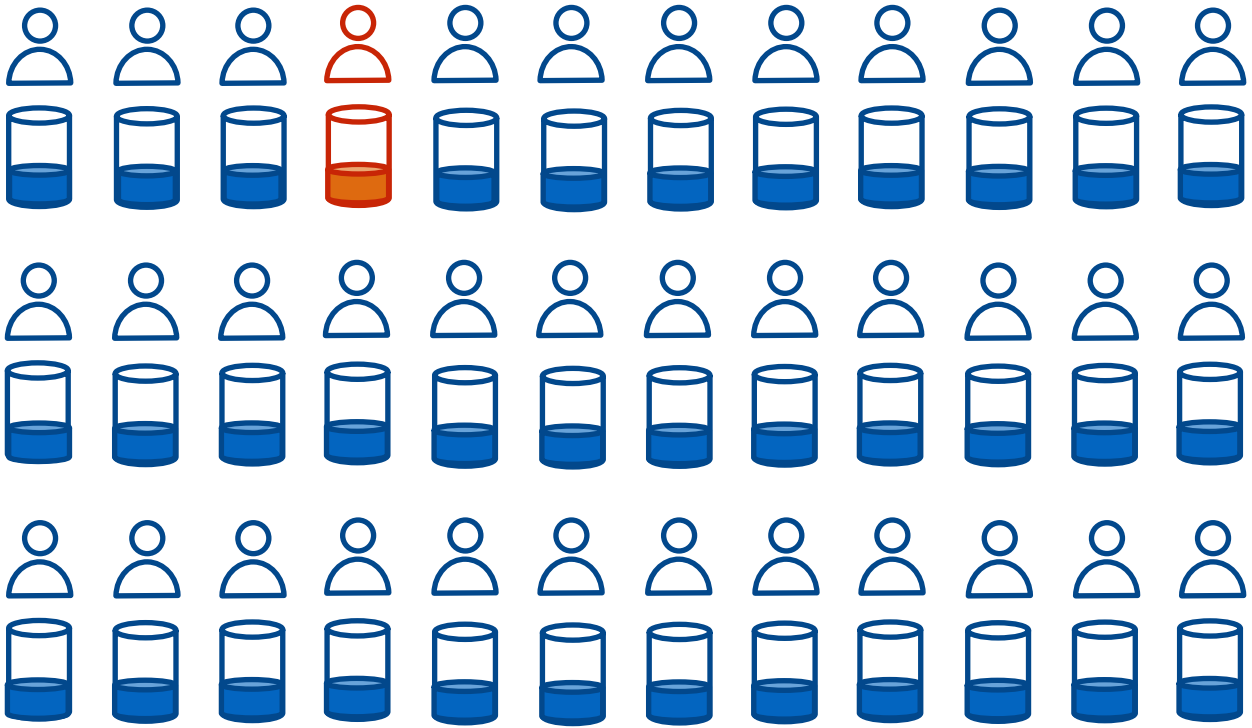
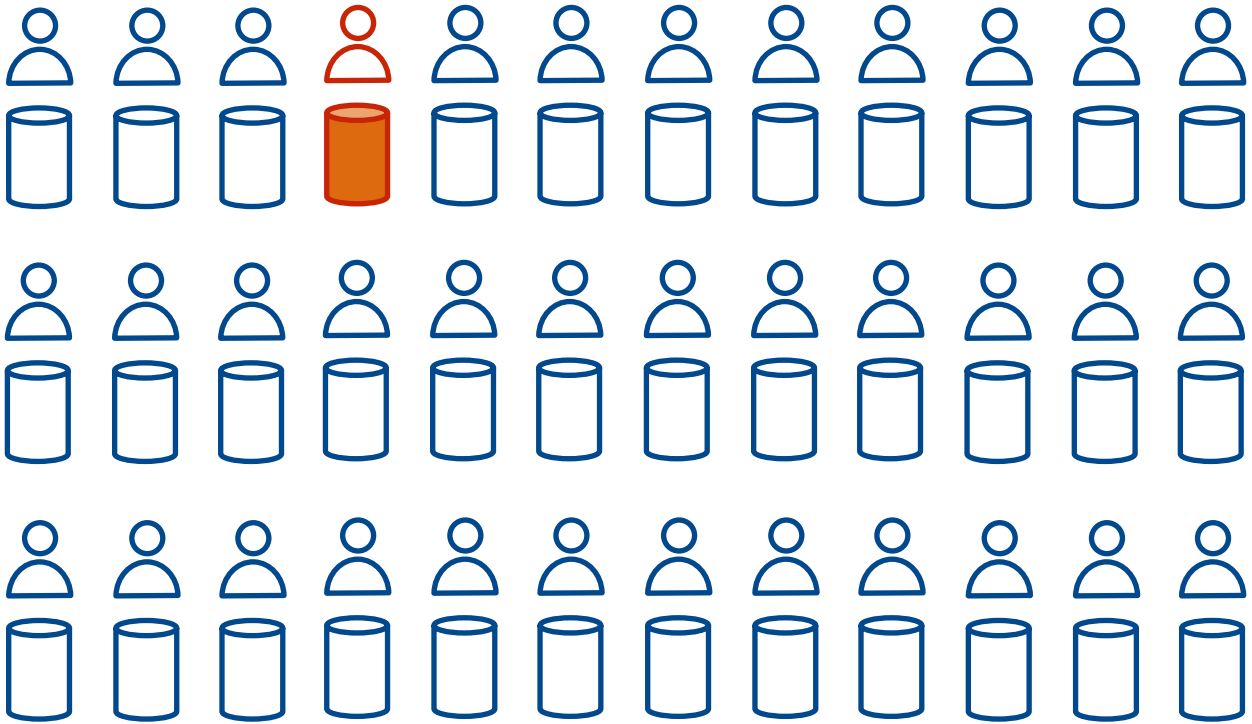


Big data: some of *everyone's* data, considered *together*

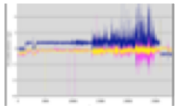
What is small data?



Small data: all of *your* data, considered *individually*

Examples of small data

Passively-recorded activity, location


Sensors, wearables



Digital traces



Smart(er) self report



Small data: passively recorded activity, location, etc.

Your mobile phone knows…

- where you are and where you've been
- how active you are
- who you talk to and what you say
- your schedule
- the sounds and conversations around you
- what's going on through the camera lens(es)
- which apps you're using
- what you're doing on the internet
- when you're sleeping
- …

e.g. Aware Framework

Small data: sensors and wearables

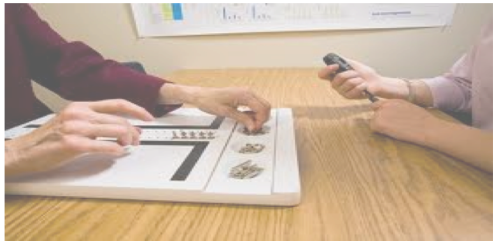
Magic Mirror

Small data: digital traces

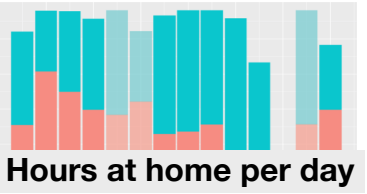
Small data: smart(er) self report

Making sense of small data: moving up the data food chain

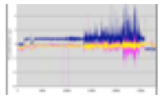
patient function
(behavioral biomarkers)



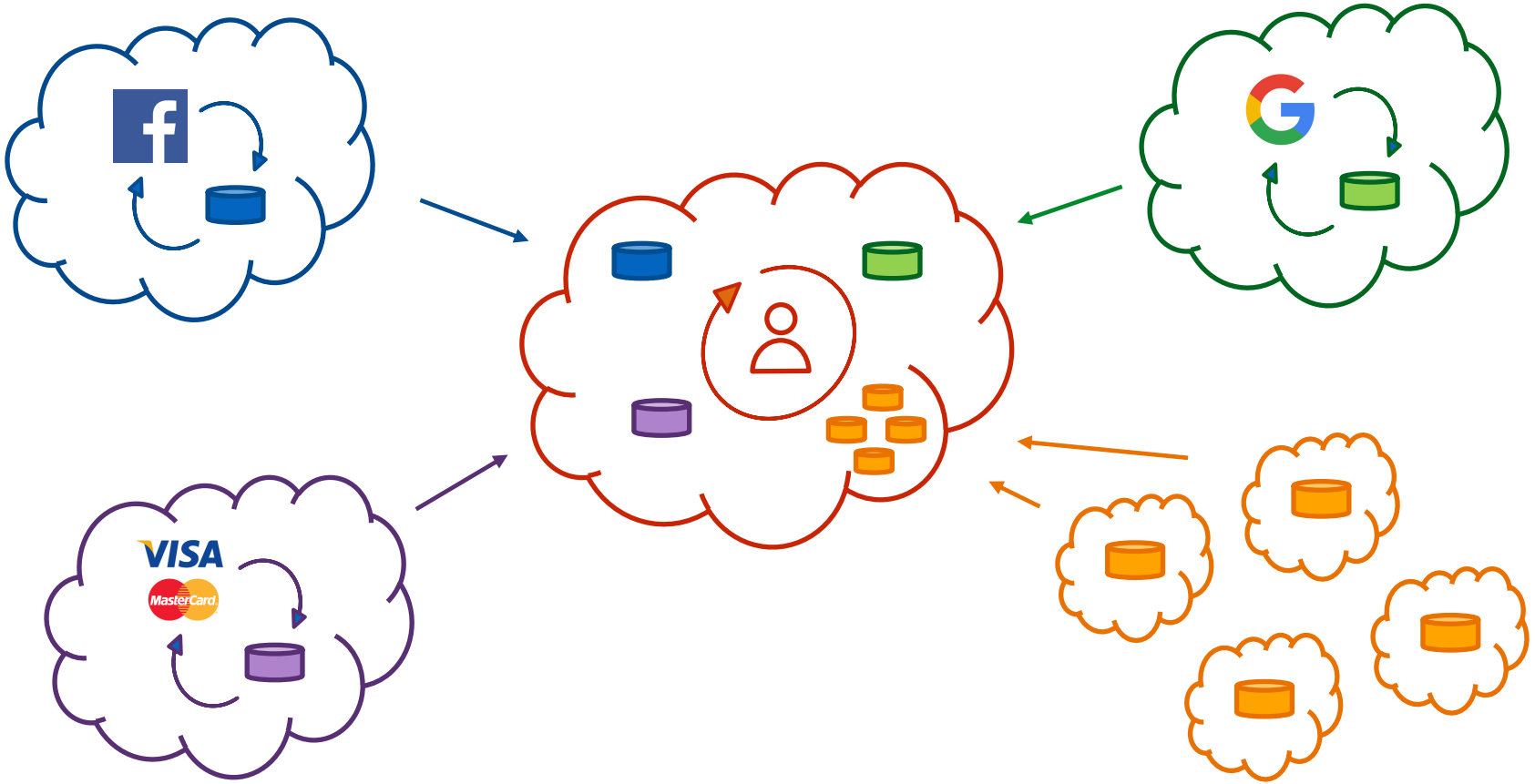
summarization, fusion



raw measurements



Personal models derived from small data



Part 2: Improving self report with mobile tech

Smartphones are the ideal data collection platform

Always with us

Intimately knowledgeable about us

Can sense our context

Interrupt us at will

Engineered to be super easy to use

The more things change the more they stay the same

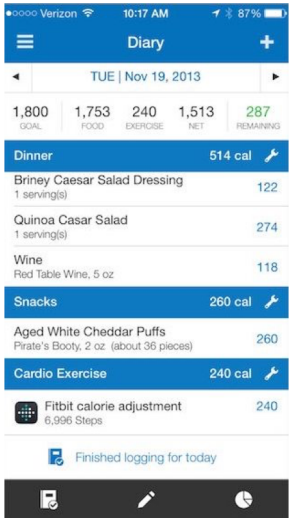
1955

Food Diary

Week of _____

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday	Symptoms
Breakfast									
Snack									
Lunch									
Snack									
Dinner									

2017



How should we self report instead?

Ideally, mobile phone-based self report should be:

Adaptable ✓

Personalized ✓

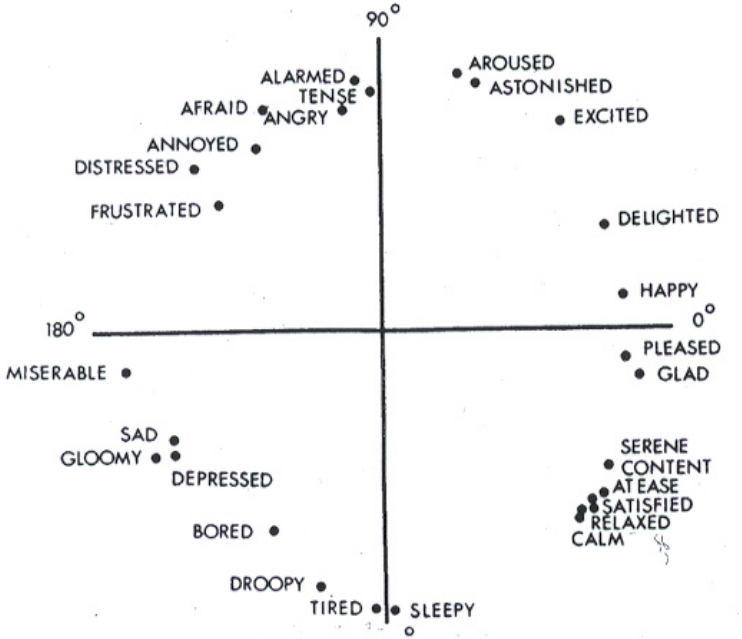
Context-sensitive ✓

Quick and easy ✓

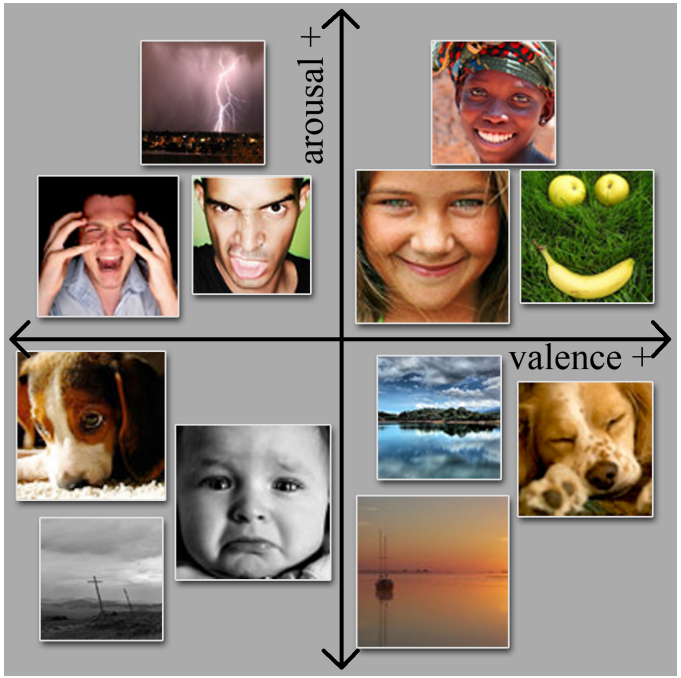
PAM: the Photographic Affect Meter

(Pollak, et al 2011)

PAM: the Photographic Affect Meter



Russell's Circumplex Model of Affect



Emotion-tagged photos in PAM

Validation is key

Example from the validation path for PAM:

1. Prototype, establish face validity with clinicians and patients

2. Correlational analysis between PAM and PANAS, POMS, SAM, Affect Grid

3. Traditional mood induction experiment

4. Demonstrate expected relationships between PAM and related outcomes in studies

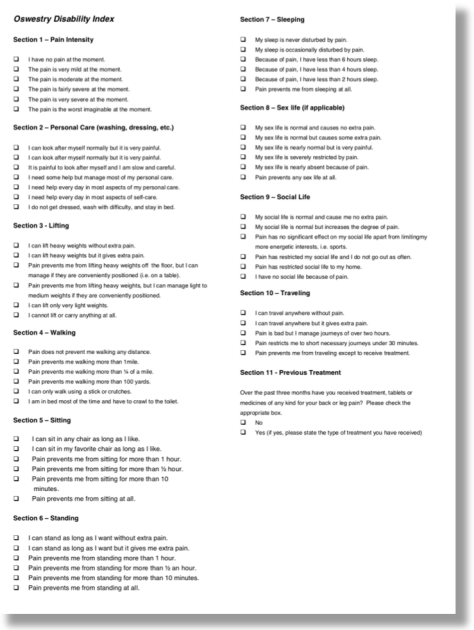
5. Achieve wider adoption and ultimately acceptance in research community

AVA: Adaptable Visual Assessment

A new platform for quickly developing a better breed of mobile assessments

AVA: Adaptable Visual Assessment

Step 1: improve the standardized questionnaire



Oswestry Disability Index

Section 1 – Pain Intensity

- ❑ I have no pain at the moment.
- ❑ The pain is very mild at the moment.
- ❑ The pain is moderate at the moment.
- ❑ The pain is fairly severe at the moment.
- ❑ The pain is very severe at the moment.
- ❑ The pain is the worst imaginable at the moment.

Section 2 – Personal Care (washing, dressing, etc.)

- ❑ I can look after myself normally but it is very painful.
- ❑ I can look after myself normally but it is very painful.
- ❑ It is painful to look after myself and I am slow and careful.
- ❑ I need some help but manage most of my personal care.
- ❑ I need help every day in most aspects of my personal care.
- ❑ I need help every day in most aspects of self-care.
- ❑ I do not get dressed, wash with difficulty, and stay in bed.

Section 3 - Lifting

- ❑ I can lift heavy weights without extra pain.
- ❑ I can lift heavy weights but it gives extra pain.
- ❑ Pain prevents me from lifting heavy weights off the floor, but I can manage if they are conveniently positioned (i.e. on a table).
- ❑ Pain prevents me from lifting heavy weights, but I can manage light to medium weights if they are conveniently positioned.
- ❑ I can lift only very light weights.
- ❑ I cannot lift or carry anything at all.

Section 4 – Walking

- ❑ Pain does not prevent me walking any distance.
- ❑ Pain prevents me walking more than 1mile.
- ❑ Pain prevents me walking more than ¼ of a mile.
- ❑ Pain prevents me walking more than 100 yards.
- ❑ I can only walk using a stick or crutches.
- ❑ I am in bed most of the time and have to crawl to the toilet.

Section 5 – Sitting

- ❑ I can sit in any chair as long as I like.
- ❑ I can sit in my favorite chair as long as I like.
- ❑ Pain prevents me from sitting for more than 1 hour.
- ❑ Pain prevents me from sitting for more than ½ hour.
- ❑ Pain prevents me from sitting for more than 10 minutes.
- ❑ Pain prevents me from sitting at all.

Section 6 – Standing

- ❑ I can stand as long as I want without extra pain.
- ❑ I can stand as long as I want but it gives me extra pain.
- ❑ Pain prevents me from standing more than 1 hour.
- ❑ Pain prevents me from standing for more than ½ an hour.
- ❑ Pain prevents me from standing for more than 10 minutes.
- ❑ Pain prevents me from standing at all.

Section 7 – Sleeping

- ❑ My sleep is never disturbed by pain.
- ❑ My sleep is occasionally disturbed by pain.
- ❑ Because of pain, I have less than 6 hours sleep.
- ❑ Because of pain, I have less than 4 hours sleep.
- ❑ Because of pain, I have less than 2 hours sleep.
- ❑ Pain prevents me from sleeping at all.

Section 8 – Sex life (if applicable)

- ❑ My sex life is normal and causes no extra pain.
- ❑ My sex life is normal but causes some extra pain.
- ❑ My sex life is nearly normal but is very painful.
- ❑ My sex life is severely restricted by pain.
- ❑ My sex life is nearly absent because of pain.
- ❑ Pain prevents any sex life at all.

Section 9 – Social Life

- ❑ My social life is normal and cause me no extra pain.
- ❑ My social life is normal but increases the degree of pain.
- ❑ Pain has no significant effect on my social life apart from limiting my more energetic interests, i.e. sports.
- ❑ Pain has restricted my social life and I do not go out as often.
- ❑ Pain has restricted social life to my home.
- ❑ I have no social life because of pain.

Section 10 – Traveling

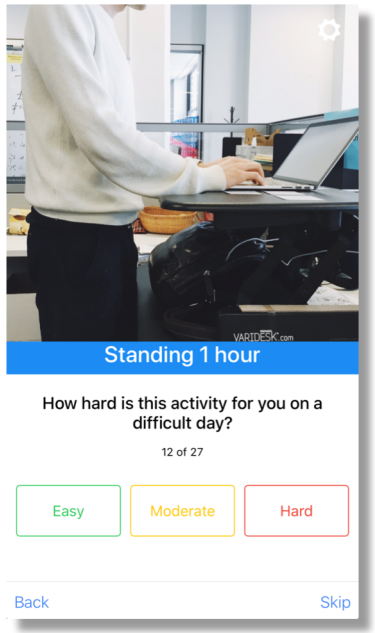
- ❑ I can travel anywhere without pain.
- ❑ I can travel anywhere but it gives extra pain.
- ❑ Pain is bad but I manage journeys of over two hours.
- ❑ Pain restricts me to short necessary journeys under 30 minutes.
- ❑ Pain prevents me from traveling except to receive treatment.

Section 11 - Previous Treatment

Over the past three months have you received treatment, tablets or medicines of any kind for your back or leg pain? Please check the appropriate box.

- ❑ No
- ❑ Yes (if yes, please state the type of treatment you have received)

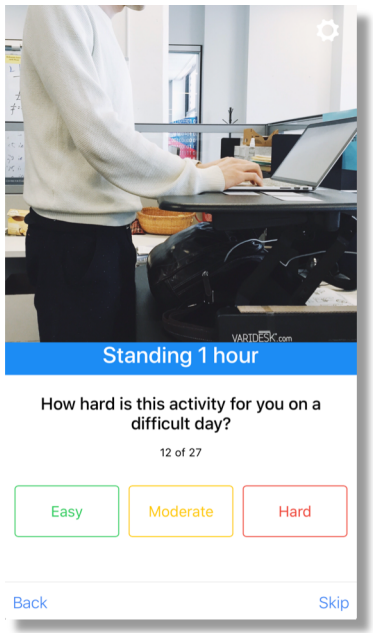
Can we replace this

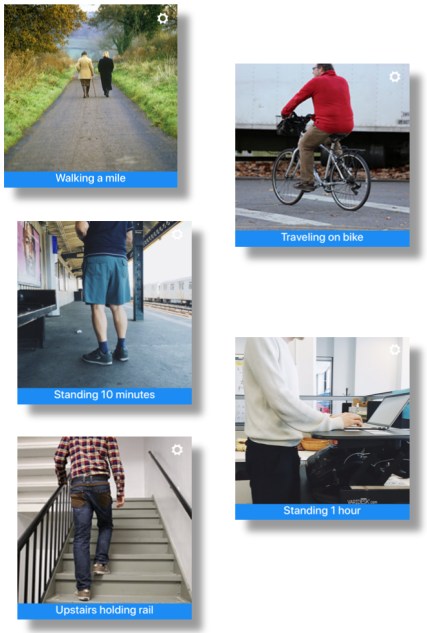


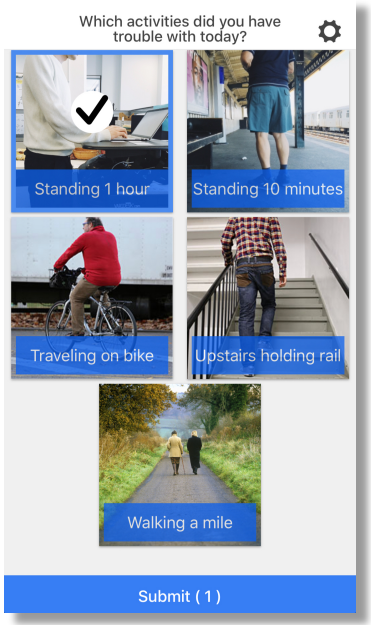
... with this

AVA: Adaptable Visual Assessment

Step 2: introduce personalized, daily reporting





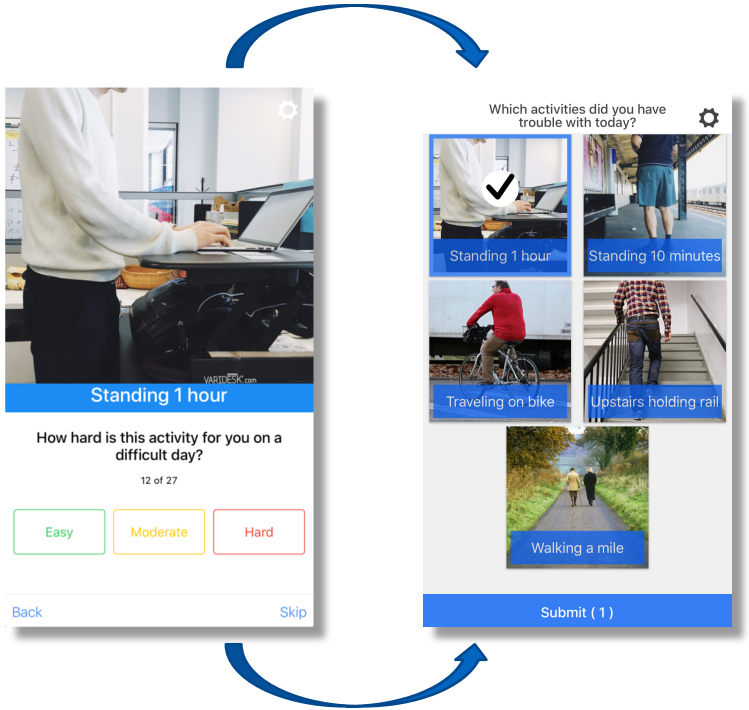


Filter down to only the relevant items

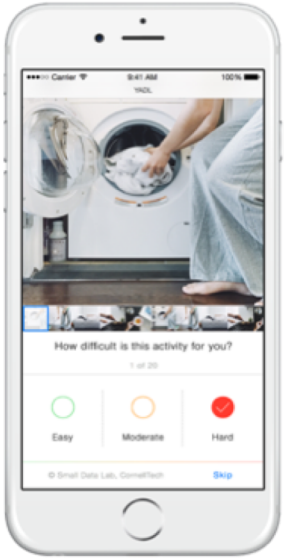
For a personal assessment

AVA: Adaptable Visual Assessment

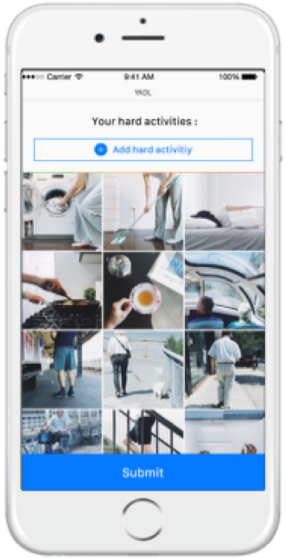
Reassess for ongoing adaptability and personalization of items



AVA example: low back pain

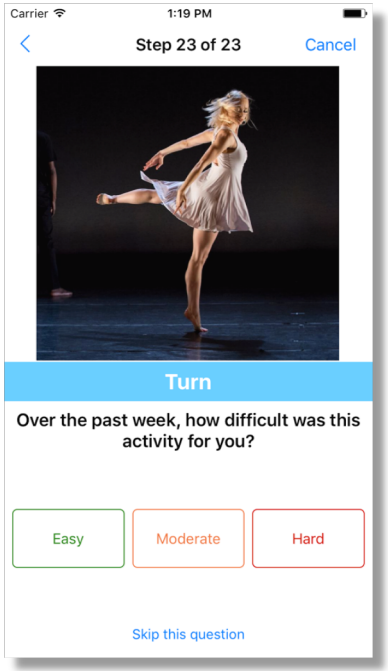


Monthly Identification of Painful/ Difficult/Interfered-with ADLs
http://bit.ly/1KoqUIP

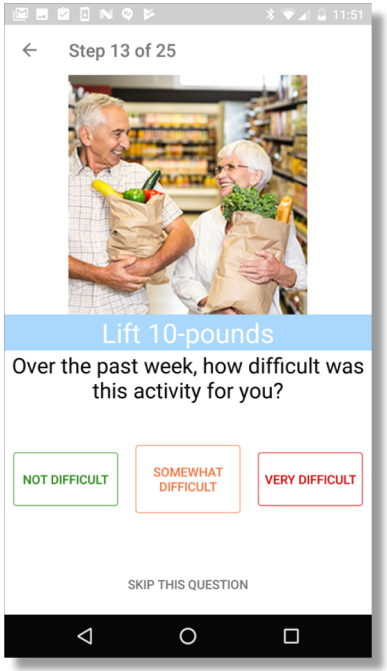


Daily Assessment of ADLs that were Painful/Difficult/Interfered-with that day

AVA further examples



Dance-related injury
Leiderbach, et al NYP

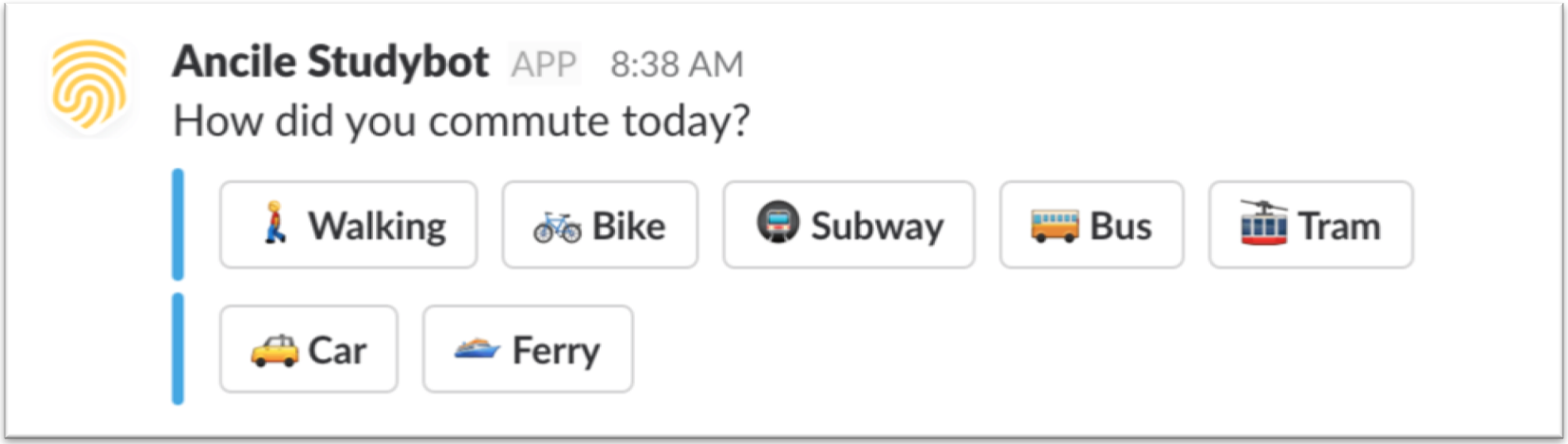


CHF
Dodson, et al NYU

Stroke
Post-op recovery
Rheumatoid Arthritis
Depression
Anxiety
Impulsivity

Others in progress

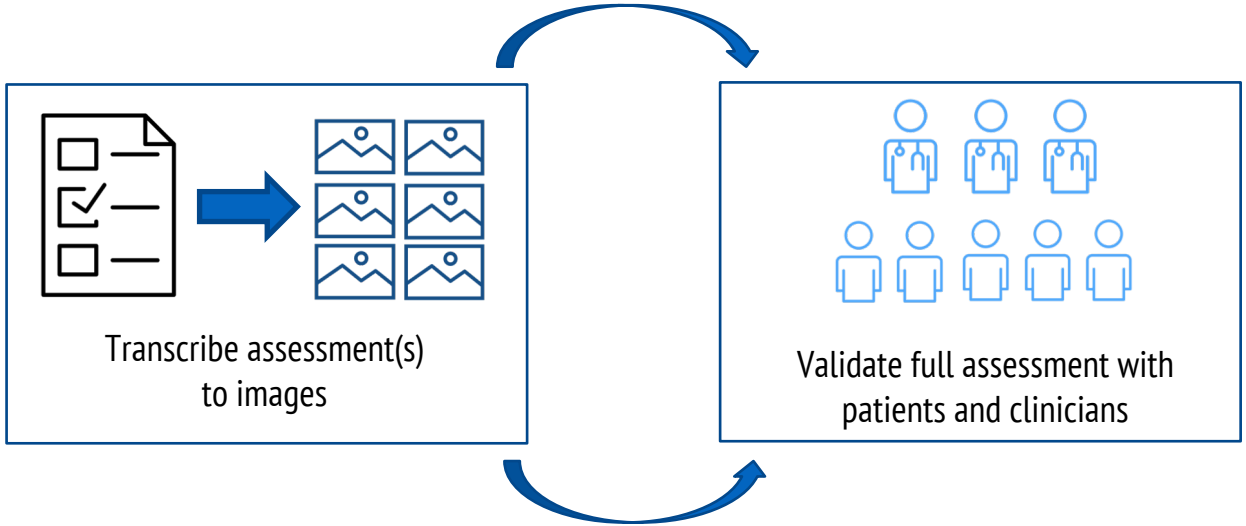
AVA as “chatbot”



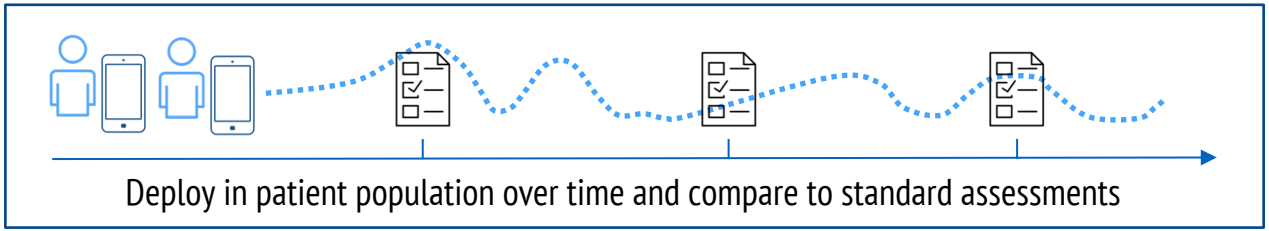
Studybot

AVA development process

Phase 1

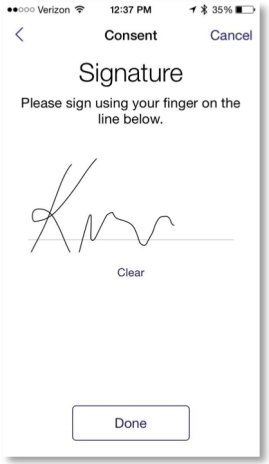


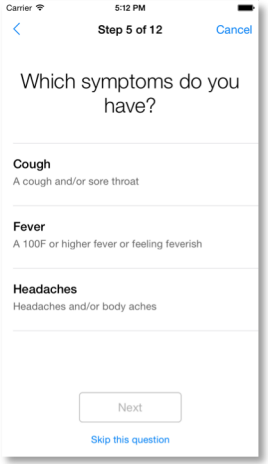
Phase 2



Part 3: Applications & interventions

Collecting small data: ResearchKit & ResearchStack





Modular architecture: Active and Passive Tasks + Surveys

Standardized UX

Reusable and sharable

Consent, privacy and security, data sharing and reuse

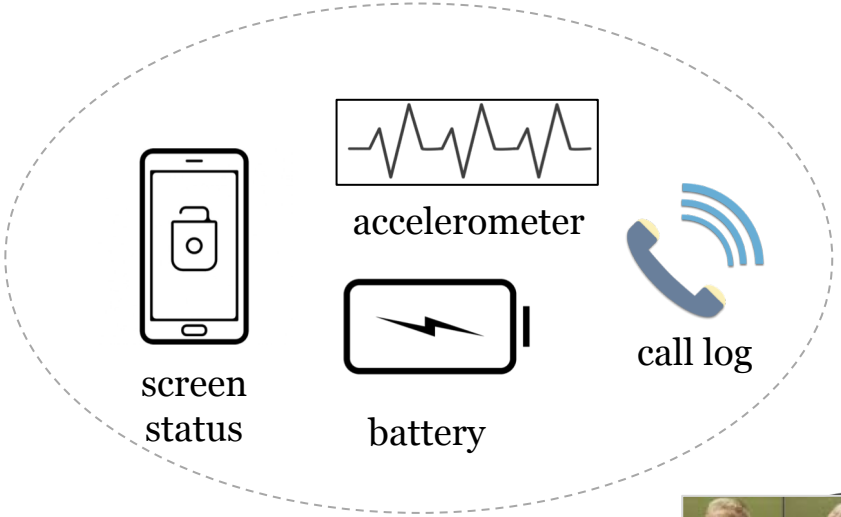
Sage BIONETWORKS

Open mHealth

touchlab

Example: the Digital Marshmallow Test

Can we build a personalized model of one's impulsive behavior?

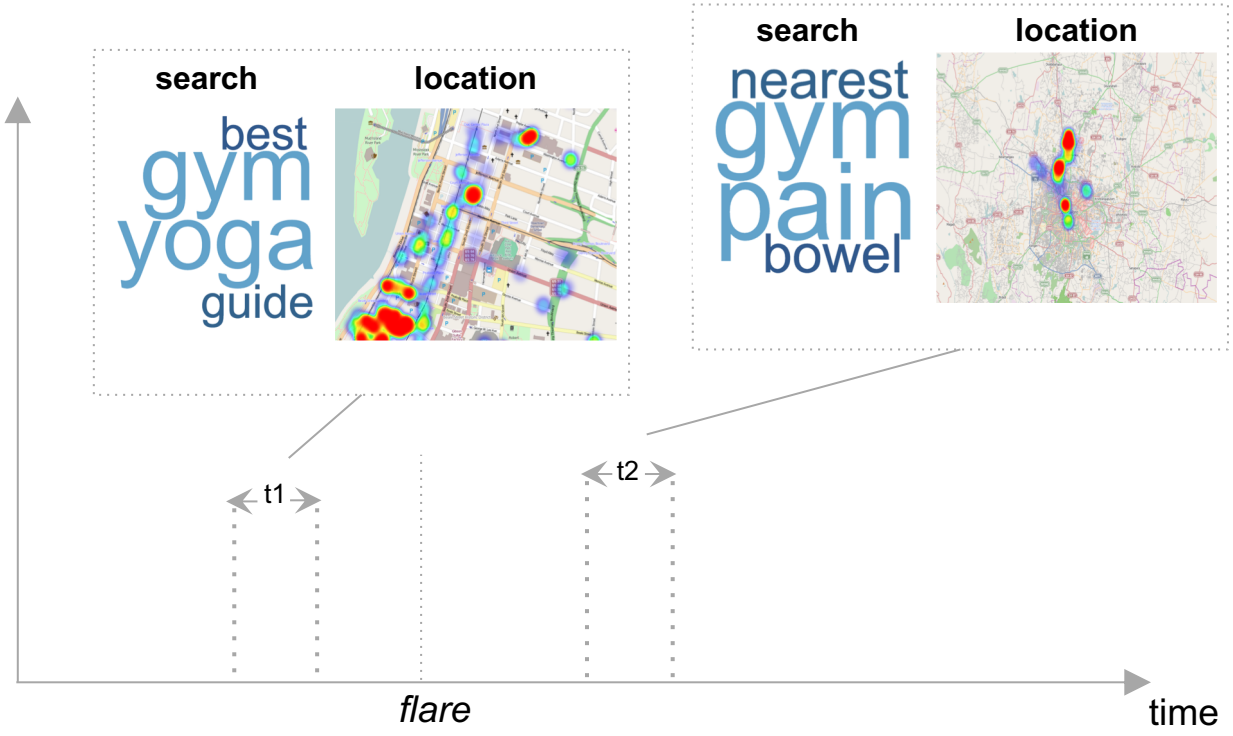


Northwell Health℠ PI Fred Muench

ResearchSuite

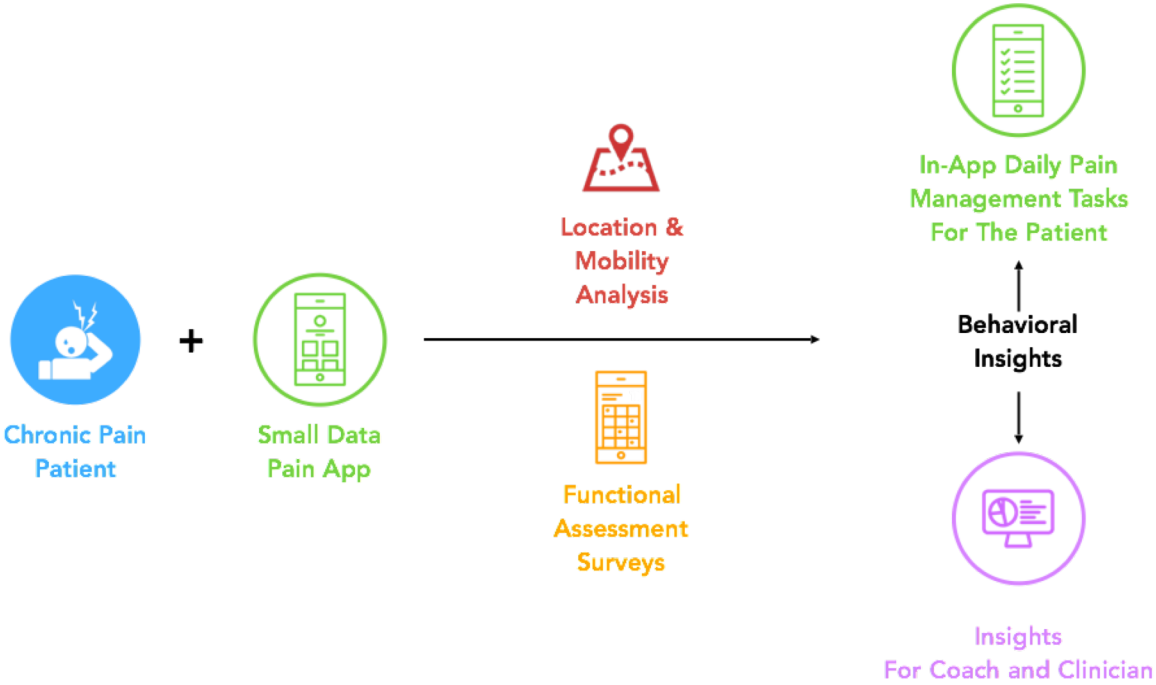
Example: Retrospective Data Learning

Can we identify flares and remission using search and location histories from Google Takeout?



Example: Limbr

Can personalized models of recovery-related behavior improve adherence?



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Thank you