# This document has been archived and is no longer updated! You can find the current document for the year 2021 here.

Open Humans Community Call 2021

## Open Humans Community Calls And Self-Research Chats - 2020

This document has information for our community calls, and is a running agenda & shared notes document.

There are currently two kinds of regular community calls:

**Community Calls (monthly, second Tuesday):** focus on anything of interest to the OH community, including infrastructure, program, management, tools, projects, collaborations, etc. etc. Feel free to bring any OH relevant topic to these calls. These calls are typically recorded.

**Self Research Chats (weekly on Thursdays):** These weekly calls grew out of the <u>Steven Keating Memorial Self-Research Project</u> on Open Humans. These chats are focused on supporting our self research projects. Bring your projects, ideas, progress, and insights. You are welcome to present or just listen. These calls are typically NOT recorded.

#### Call information:

- 1. **Time:** 10:00am PST (18:00pm GMT)
- 2. Zoom videochat meeting link: https://zoom.us/i/196519106 Passcode: 922125
- 3. **Open Humans Community calendar:** <a href="https://tinyurl.com/sfglmx8">https://tinyurl.com/sfglmx8</a>
  If you use Google Calendar, you can use a button on the bottom right to add this to your calendar.
- 4. Meeting agenda & notes (this document): https://tinyurl.com/wprwl2bEditing this document:
- Use "suggestion mode" to add your name and/or ideas to an upcoming call.
- We'll make the document editable during calls, please be invited to contribute to note-taking!

We also use Slack a lot to chat - you're welcome t join! Get access here: http://slackin.openhumans.org/

#### Meeting links:

February 04 (Self-Research Chat)

January 28 (Self-Research Chat)

January 21 (Self-Research Chat)

January 12 (Community Call) January 7 (Self-Research Chat) December 17 (Self-Research Chat) December 10 (Self-Research Chat) December 08 (Community Call) December 03 (Self-research chat) November 26 (Self-research chat) November 19 (Self-research chat) November 12 (Self-research chat) November 05 (Self-research chat) October 29 (Self-research chat) October 22 (Self-research chat) October 15 (Self-research chat) October 11 (Community Call – mostly skipped) October 8 (Self-research chat) October 1 (Self-research chat) September 17 (Self-research chat) September 10 (Self-research chat) September 8 (Community Call – Autistica/Turing CitSci) September 3 (Self-research chat) August 27 (Self-research chat) August 20 (Self-research chat) August 13 (Self-research chat) August 6 (Self-research chat) August 4 (Community Call - Design/UI/UX of Open Humans) July 30 (Self-research chat) July 28 (Community Call) July 23 (Keating Memorial Show&Tell) July 21 (Quantified Flu Community Call) July 16 (Self-research chat)

July 14 (Community Call)

July 09 (Self-Research chat)

July 07 (Community Call)

July 02 (Self-research chat)

June 30 (Community Call)

June 25 (Self Research Chat)

June 23 (Community Call)

June 18 (Self-research chat)

June 16 (Community Call)

June 11 (Self-research chat)

June 9 (Community call)

June 4 (Self-research chat)

June 2 (Community Call)

May 28 (Self-research Chat)

May 26 (Community Call)

May 21 (Self-Research Chat)

May 19 (Community Call)

May 12 (Community Call)

May 7 (Self research chat)

May 5 (Community call)

April 30 (Self research chat)

April 28

April 23 2020 (Self research updates)

April 21 2020 (COVID-19 related projects & features)

April 14 2020

March 26 2020

March 10 2020

February 11 2020

<u>January 14 2020</u>

December 10 2019

## February 04 (Self-Research Chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom video chat link: <a href="https://zoom.us/j/196519106">https://zoom.us/j/196519106</a> Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/y5ztlnvh">https://tinyurl.com/y5ztlnvh</a>

#### Attendees:

- Bastian Greshake Tzovaras
- Gary Wolf
- Mad Ball
- James Littlejohn
- Richard Sprague
- Shelbey Rolison
- Herman de Vries
- David Blackwell
- Miguel
- Dimitri
- Abhik Chowdhury
- Enric
- Add your name!

#### Topics:

- The next Keating Memorial!
  - Timeline, kickoff meeting
- Bastian made a little dashboard, can share this
- Richard didn't plan to share but I do have something about VO2 max vs cholesterol levels
- Miguel have something to share, a dashboard I use
- James nothing to present but a question I've been thinking/wondering about is "how are people sure a data trend is a 'good trend' ... what context they put that in (immediate, over months, lifetime) -- Gary: I'm interested in this, connects to something I've been thinking about
- Abhik no update but I did get a new ecg monitor, since gary's here would be interested in what he thinks
- Dave got genomic data from nebula
- Shelbey communication-based NSF study on self-trackers, would like to talk with self-trackers 1-on-1, \$50 gift card as thank you for participants: srolison@utexas.edu

- Keating memorial
  - Kickoff meeting next Thursday
    - Ask: We will want to have a couple folks that can share a project (idea, in progress, finding) -- as is routine -- next week, so newcomers can see the typical go around & how it works
  - Show & Tell will be July 22nd
  - There will be a new fresh google doc for notes for the meetings starting next week: <a href="https://docs.google.com/document/d/1p61Zp48JXYxc5tB2q7WR51ZQ8\_TS0s8-LDtvVSC88QA/edit#">https://docs.google.com/document/d/1p61Zp48JXYxc5tB2q7WR51ZQ8\_TS0s8-LDtvVSC88QA/edit#</a>

- Miguel, sharing dashboard
  - https://www.home-assistant.io/getting-started/
  - https://miguelrochefort.com/blog/calendar/
- Richard: looking at Apple Watch-calculated VO2 Max levels
  - Why a sudden plunge since July?
  - Does it related to the resting heart calculations in the OH Jupyter notebook
  - Bastian: hack to get better VO2 numbers: walk faster.
- Abhik's low power ECG
  - <a href="https://www.tindie.com/products/ultimaterobotics/uecg-smallest-open-low-power-ecg/">https://www.tindie.com/products/ultimaterobotics/uecg-smallest-open-low-power-ecg/</a>
  - https://www.tindie.com/products/ultimaterobotics/uecg-smallest-open-low-power-ecg/
  - https://hackaday.com/2019/11/08/uecg-a-very-small-wearable-ecg/

## January 28 (Self-Research Chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom video chat link: https://zoom.us/j/196519106 Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/y5ztlnvh">https://tinyurl.com/y5ztlnvh</a>

#### Attendees:

- Bastian Greshake Tzovaras
- James Littlejohn
- Enric Senabre
- Miguel
- Dm
- Kate
- Abhik
- Shelbey
- David Blackwell <a href="https://my.pgp-hms.org/profile/huFE0257">https://my.pgp-hms.org/profile/huFE0257</a> Atrial Fibrillation, Eliquis, CPAP, B12, D3, Zinc, B1 Thiamine

#### Topics:

- Enric: Small update on an intervention on sleep quality done before Christmas
- Abhik: some more diagramming of data flows

#### Notes:

- Next Keating Memorial: will have a new deadline and announcement by next week hopefully
- Enric: Investigating what activities or conditions influence the quality of sleep & dreams? And does it correlate with mood + self-perceptions after sleeping/dreaming?
  - Tracking activities + mood w/ Daylio + qualitative notebook, tracking sleep with fitbit
  - Overview of Daylio categories, tracking besides mood:
    - Dreams.
    - Pre-sleep activities
    - Daily activities
    - Places visited
    - Weather
  - Nightmares co-occurring with confused, healing dreams with good mood items
  - Fitbit data:
    - Initially observing interruptions in sleep, might be effect of wanting to note down dreams, priming oneself for waking up
    - Currently hard to make sense out of the data
  - Customizing Daylio was not useful
  - For dream diary: needs to be the first activity in the morning, otherwise the detail of the memory drops

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## January 21 (Self-Research Chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom video chat link: https://zoom.us/j/196519106 Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/y5ztlnvh">https://tinyurl.com/y5ztlnvh</a>

#### Attendees:

- Bastian Greshake Tzovaras
- Add your name below!

Jon Cousins

- James Littlejohn
- Shelbey Rolison
- Gary Wolf
- Abhik
- Dm
- David Blackwell <a href="https://my.pgp-hms.org/profile/huFE0257">https://my.pgp-hms.org/profile/huFE0257</a> Atrial Fibrillation, Eliquis, CPAP, B12, D3, Zinc, B1 Thiamine

#### Topics:

- Have something you want to share? Add your topic!
- Abhik: Structuring and storing all of the data, how to do it?
- Gary: some project updates

#### Notes:

- Gary: Tracking arrhythmias for around a year now

## January 12 (Community Call)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

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Recurring calendar event: <a href="https://tinyurl.com/y5ztlnvh">https://tinyurl.com/y5ztlnvh</a>

#### Attendees:

- Add your name below!
- Mad
- Ben Carr
- Gary Wolf
- David Blackwell
- Miguel Rochefort
- Enric Senabre Hidalgo

#### Notes:

- Observable Notebooks as embedded data sharing
  - <a href="https://observablehq.com/">https://observablehq.com/</a>
  - https://github.com/observablehg

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## January 7 (Self-Research Chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: <a href="https://zoom.us/i/196519106">https://zoom.us/i/196519106</a> Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/y5ztlnvh">https://tinyurl.com/y5ztlnvh</a>

#### Attendees:

- Bastian
- Katarzyna Wac
- James Littlejohn
- Jonathan Ward (projectaligned on the forum)
  - Latest post https://forum.quantifiedself.com/t/statistics-how-many-rows-did-you-need-to-get-a-robust-p attern/8848
- Abhik Chowdhury
- David Blackwell <a href="https://my.pgp-hms.org/profile/huFE0257">https://my.pgp-hms.org/profile/huFE0257</a> Atrial Fibrillation, Eliquis, CPAP, B12, D3, Zinc, B1 Thiamine
- Miguel

#### Topics:

- Dimitri: typing speeds & ABPM

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#### Notes:

- Go here

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## December 17 (Self-Research Chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: <a href="https://zoom.us/j/196519106">https://zoom.us/j/196519106</a> Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/y5ztlnvh">https://tinyurl.com/y5ztlnvh</a>

#### Attendees:

- Bastian
- Gary
- Katarzyna Wac
- David Blackwell
- Miguel
- Paula (will join a bit later)
- Abhik Chowdhury
- Shelbey

#### Topics:

- Gary:
  - QS Meeting
  - Writing "Personal Science: Learning to observe"

- QS Show & Tell on January 14th at same time slot as the usual self-research meeting, sign-up at https://docs.google.com/forms/d/e/1FAIpQLScUW475d4rKRqI\_VSVrSvYyZqq9xAjSKpxRhAIWLtvaAS-7 RA/viewform
- Patterns of reasoning
  - Bastian: There are interesting examples in the general data viz field for how to pick the right visualization for your data:
    - <a href="https://www.data-to-viz.com/">https://www.data-to-viz.com/</a> (interesting decision trees)
    - <a href="https://datavizcatalogue.com/">https://datavizcatalogue.com/</a> (has a nice "search by function" tool)
    - <a href="https://datavizcatalogue.com/">https://datavizcatalogue.com/</a> (also gives some 'families' of data visualizations & functions)

## December 10 (Self-Research Chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: <a href="https://zoom.us/j/196519106">https://zoom.us/j/196519106</a> Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/y5ztlnvh">https://tinyurl.com/y5ztlnvh</a>

#### Attendees:

- Bastian
- James
- Abhik
- Katharina
- Shelbey
- Miguel
- Add your name below!

#### Topics:

- Abhik: Different wearables & getting data off them
- James: Personalization of algorithms
- Miguel: Time tracking of bachelor thesis
- Bastian: nothing new, but last week's data viz: https://tzovar.as/app-related-stress/

#### Notes:

- Miguel:
  - Time tracking across degree, using both ActivityWatch and manual tracking
- Abhik
  - Comparing sleep data, big differences between in-bed sensor, Fitbit & Oura ring, all with own limitations of what is being identified

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## December 08 (Community Call)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: <a href="https://zoom.us/j/196519106">https://zoom.us/j/196519106</a> Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/y5ztlnvh">https://tinyurl.com/y5ztlnvh</a>

#### Attendees:

- Bastian
- Add your name below!

#### Notes:

- The GWAS

## December 03 (Self-research chat)

10:00 PDT / 13:00 EDT / 17:00 BST / 19:00 CEST

Zoom videochat link: <a href="https://zoom.us/j/196519106">https://zoom.us/j/196519106</a> Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/y5ztlnvh">https://tinyurl.com/y5ztlnvh</a>

#### Attendees:

- Bastian Greshake Tzovaras
- Richard Sprague
- Gary Wolf
- James Littlejohn
- Mad Ball
- Herman de Vries
- Shelbey Rolison
- David Blackwell
- Kat Wac
- Miguel Rochefort
- Paula Leonova
- Add yourself:)

#### Topics:

- Bastian little thing about association of applications on computer with heart rates
- Richard show playing with Amazon Halo, get ideas
- James (maybe?) trying a new Chinese wearable
- Go here

- Richard Amazon Halo
  - Believe it's in beta or something, got access to it last week.
    - Uses an app, can see live heartrate in that.
  - Has a built in microphone
    - if you run the app live, it seems to detect words? tone? and gives summary about tone of the conversation.
    - Summary about "mood" over the day based on tone of voice.
  - Scan of the body using the phone follow instructions "turn left, turn right" claims to have captured a measure of body fat.
  - Questions: can I get the raw data myself? Can I trust that it's accurate?
    - To get data: request it, emails a link, downloaded data is in folders (Activity, Body, Sleep, Tone, PrivacySetings, ProfileInformation) various files inside, json and csv.
    - Tried to compare Apple Watch vs. Amazon Halo heartrate data
    - Plot of Resting Heart Rate over the week of wearing both
      - Very different? (Halo ~5 bpm more) and seem like they're not even moving the same direction together
    - Did same with raw data (minute to minute), seemed like it wasn't correlated very well either
  - Kat: reassuring the microphone isn't always on

- Richard: no, it is always on I was just showing a session I could watch, but it's continuously recording and creating daily summaries of what you're saying
  - Richard: that's right, it continuously infers mood from the microphone and speaking... for example yesterday shows 4:50pm as the time I was most "positive"
- Gary: anything you've heard about speculated use case for this microphone tone measuring?
  - Richard: I think it's trying to produce an objective quantitative measure of mood.
  - Gary: I've seen speculative use-cases for this sort of future; but almost all of them suggest a triggered notification or prompt (e.g. alert)
  - David: seems like it's showing off their machine learning capabilities. I think it's interesting, wondering to what extent it's based on the words themselves vs. the tone of voice.
  - Gary: I'm curious about "why" they're doing it. When people analyze vocabulary alone (text only) it's not very effective to determining mood. Maybe with audio and tone it will be more effective.
- Kat: the heartrate, was that at night?
  - Richard: I don't know how they compute it; I don't know how Apple does either though.
  - Richard: tried to do a correlation of the raw data
    - Mad: visually they look correlated at least
    - Gary: looks like Apple is more variable
    - Richard: I can't seem to get the Halo to get a number over 130
- Mad: the mood thing is interesting, but only works if you're talking really depends on context, can't guess mood outside that.
  - Richard shared the display again two axes (positive/negative; energy); Herman: looks like the arousal / valence model for mood.
- James COLMI smartwatch; not much to share
  - Gary: feels like manufacturing capacity for these devices is so large now; James: I think it shifts attention and control over algorithms.
- Bastian looking at heartrate correlations
  - initially attempted to correlate music listening habits (Spotify) vs. heartrate couldn't manage it, trying to filter and bin the heartrate data by music was too much data.
  - Worked better trying to use RescueTime, which has started giving 5 minute intervals for what apps were being used. (Used to be hourly reports).
    - Used the rule "more than a third of the interval" for filtering heartrate by app use
  - Plotting...
    - vs "productivity level" according to RescueTime
      - these all look pretty much the same
    - vs. "application category" according to RescueTime (e.g. "Writing", "Data modeling & Analysis"
      - somewhat more differences
    - vs. "individual application"
      - these look most interesting
      - e.g. Keynote: looks like it might be a combination of two distributions, reflecting preparation vs. presentations
      - similar "two peaks" with Open Humans notebooks is that R vs python? Rstudio vs. atom (used for Python) also have different profiles, I think R programming is probably more stressful for me than python.
  - Time of day may also be a factor... e.g. netflix is late, maybe that's why it's usually higher? But VLC media player is also late, and it's much lower heartrate so maybe related to the types of media for those.

- Wondering if Herman has further ideas.
- Herman: these are all captured while sitting?
  - Bastian: it's computer usage so that's true; maybe sometimes it's higher because you "just sat down"
- Paula: do you have the pro version of rescuetime? (Bastian: yes) I think you might have to turn it on to get it, but you can record specifics about what you're doing, e.g. when I'm coding it records which file I'm working on maybe for netflix or vIc it could capture that
- Bastian: Plotted all the data according to time of day; biggest change seems to be early in the day (just arrived at office)
  - Richard: it all looks the same but breaking the data by source would reveal more differences
- Herman: it could also be that there's long term changes in heart rate that's entangled with long term changes in which apps you're using most
- Paula: I wonder if you can use location data to determine what you were doing, e.g. presenting at a meeting
  - Bastian: still tough to distinguish between presenting at work vs. prep for presenting... since the pandemic there isn't much location changing anyway
- Miguel: is there any equivalents for iOS time-tracking?
  - Bastian: there's moment, but it's about usage overall -- there's just a hacky attempt to use screenshots to determine which apps got used
    - Herman: I think they've removed that too recently
  - Bastian: I don't understand why this sort of data isn't exportable from the phone. e.g. into healthkit would be nice.
  - Gary: you can't export phone use data from apple phones? Bastian: correct
  - Bastian: I think RescueTime does exist for Android. Paula: yes, they removed/lost browser URL tracking but do app tracking.
- Link to the notebook: <a href="https://tzovar.as/app-related-stress/">https://tzovar.as/app-related-stress/</a>

## November 26 (Self-research chat)

10:00 PDT / 13:00 EDT / 17:00 BST / 19:00 CEST

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Recurring calendar event: <a href="https://tinyurl.com/y5ztlnvh">https://tinyurl.com/y5ztlnvh</a>

#### Attendees:

- Bastian Greshake Tzovaras
- James Littlejohn
- Dave Blackwell
- Enric Senabre

#### Topics:

- Bangle.js
- Enric's project

#### Notes:

- Bangle: What are priorities?
  - Gordon says: longer battery life, better heart rate sensor
  - Also engaged on economics of it, control of data and algorithms
  - Can use Gadgetbridge that reverse-engineers closed wearables, Bangle is there too for notifications
  - Bastian: Showed the gesture recognition features at a workshop, was really great. Also seeing more use of the Puck.js as a one-button-tracker
- Enric:
  - Tracking of activities and external conditions to see how they influence sleep quality and dreaming.
  - Methods:
    - Using customized Daylio to score mood and also log additional metadata.
      - Logging every morning. Selecting which types of dreams and the previous day's activity
    - Also take some qualitative notes through a notebook (e.g. details from dreams)
    - Last but not least: Using a Fitbit for activity & sleep
    - Currently observational, but might do some interventions in the future
    - Tracking a lot of metadata, but down to 5 minutes of time for logging all of them

## November 19 (Self-research chat)

10:00 PDT / 13:00 EDT / 17:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/i/196519106 Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/v5ztlnvh">https://tinyurl.com/v5ztlnvh</a>

#### Attendees:

- Bastian Greshake Tzovaras
- Enric Senabre
- Richard Sprague
- Katarzyna Wac
- Add your name

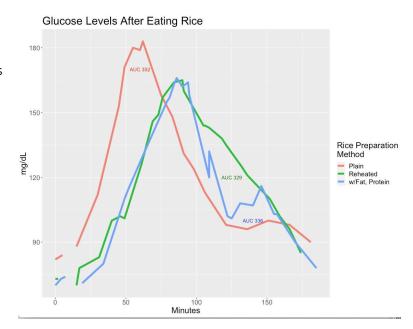
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#### Topics:

- Richard: Amazon Halo & new experiment with CGM
- Gary: Arrhythmia experiment
- Steven: New experiment

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- Richard
  - Amazon Halo
    - Voice tracking for stress measurements
    - 3D estimates of body composition
    - Want to compare to Apple Watch
    - Steven: What's the standard suite of experiments?
      - Richard: Test some nights of sleep with both devices, compare during walks,
  - CGM: In response to a question by Gary on QS forum on ketogenic diet.
     Concept of fat adaptation: Body switches over to a different fuel system and reaction to carbohydrates changes
    - Glucose levels after eating rice.
       Compare ways of preparing it.
       Comparison:
      - Plain rice
      - Reheated rice (literature says chilling/reheating causes lower glycemic index)
      - Eating with fat & protein
    - No big difference between three groups, disappointed to not reproduce published finding. Looking for other people interested in giving it a try



- Kate: What kind of rice?
  - R: japanese short grain, should have smaller impact
- Dave: Similar things for oatmeal
- Gary: Did reading on glycemic index, mainly grains. Q of processed vs whole grain, coming away with contradictory advice
- Bastian: You said that being in ketosis the results in a different processing. Might this explain it?

- R: yes, but if anything effect should be more pronounced

#### - Gary

- Keeping diary in QS forum, moving from observational into quasi-experimental mode: trying medication on a different schedule, only take when bothered by arrhythmia, seeing if it reduces incidence. First try so strong effect that assume placebo effect, but decreases in on-going events. Seems to help.
- Also tried not using drug and instead light meal and rest
- Will try this for another week and see if there is an effect
- Bastian: How will you compare the interventions? As you had a periodicity before that might complicate things?
  - G: There is probably a formula to predict next number of events based on recent past as they increase likelihood of them. But feels very complicated. Assume periodicity is due to a feedback loop
- Richard: What format is the data in?
  - G: It's from the one-button, so binary data that's time-stamped.
  - R: Might be easy if it's evenly spaced data.
  - G: Yes, it's binned by hour
- Bastian: if you have data you want to analyze, I could try to help a bit
  - Dimitri suggests: time series autocorrelation & decomposition

#### - Steven

- Clearing out apps, found many apps for novel approaches to help falling asleep (voice speaking random objects to get brain to get into the right mode, other will buzz phone). Issue with feeling anxious when falling asleep, normal approach is listening to podcasts and having familiar voices but doesn't feel like a healthy way. So trying the apps, but how do you know if they work? Working through a protocol to measure it.
- Mainly interested in approaches to do once in bed, not before-bed routines
- Enric: reminds me a bit of my interest about different interventions on falling asleep, did you consider using a fitbit for sleep phases?
  - S: was a user of the zeo and know the data can be useful, but not having developed trust/confidence in wrist-worn tools. Most useful would be 'time to fall asleep', but it's the experience of falling asleep that doesn't feel good and not the time.
  - Dave: Subject of podcasts is important for me, can't be something that i'm interested in but not caring about as i'm otherwise having harder time.
  - Mad: I did the same with public radio and agree that wearables will not help as it's about the experience and not numbers. Hard to track something when falling asleep as it interferes. Probably better to track next morning.
- Gary: Do you remember next morning of how you felt when falling asleep?
  - S: Yes, but not the time necessarily, also when sleeping alone typically getting up
- Gary: I've been there too, one method to track the time to sleep: have a mental journey walking down a road/route and note how far you get on it
- S: How long should I keep trying each method?
  - Kate: Randomizing is hard, as sleep depends on previous nights sleeps. In research we don't believe in the sleep stage metrics, but sleep duration is somewhat reliable. What actually matters is how you feel the next day? Doing vigilance tests next day
  - Mad: Wearables for time to sleep can work if you combine with keeping track of when you're trying
- Maybe answer to good way for doing the testing is there's no clever way and will take a long time
  - Mad: I'd probably take each method for a week and keep a diary
- Enric: Sleep probably also influenced by lots of other things (activity, workload), probably good to keep track of that?

-	S: yes, will try to keep track of that too. Also making sure my phone isn't a source of stimulation and rather only data entering device					
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## November 12 (Self-research chat)

10:00 PDT / 13:00 EDT / 17:00 BST / 19:00 CEST

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#### Attendees:

- Bastian Greshake Tzovaras
- Alexander Zenner
- Mad Ball
- Heman de Vries
- Dm (Dimitri)
- James Littlejohn
- Richard Sprague
- Michael Becker
- Steven Jonas
- Dave Blackwell
- Add your name)

#### Topics:

- (To be added during call)
- Alex: Short Intro + Master thesis topic
- Bastian: one-off noise analysis
- Herman: patterns of weight loss between running and cycling
- Michael: research tool that may be of interest

- Herman: working on losing weight during the pandemic, picking up an exercise routine during the lockdown
  - Weight starts to come down since lockdown starts
  - Data normalization: calculate number of standard deviations from the mean to make data comparable
  - When starting running: body fat mass keeps dropping, but weight seems to stabilize. Reason: muscle & bone mass keeps increasing under running scheme
  - Michael: What are the spikes in muscle/bone mass?
    - Herman: might be related to days of exercise where you lose lots of liquid
  - Alex: are these measured at a standard time? Michael: first thing in the morning, so it's consistent in that routine
  - Steven: reflecting on the context of the pandemic, curious about how this has potentially affected mental health.
    - Herman: difficult to say to what extent it's weight loss vs meditation vs exercise, but mental sharpness seems to have improved a lot
  - Dimitri: what sensors is withings using to distinguish muscle vs fat? Herman: don't know the tech details, it's the withings cardio scale
- Alex: sharing plans for master's thesis "app-based creation of user-centric n-of-1 trials"
  - - that is, "trial" is designed by the user rather than researcher

#### What is Alex' contact info

- Alex' contact: <u>alexander.zenner@student.hpi.de</u>
- Alex' survey: <a href="https://forms.gle/cCuGcYPwVxchq2Bs6">https://forms.gle/cCuGcYPwVxchq2Bs6</a>
- interested in what interventions, outcomes, and measures people are interested in
  - See survey above
- Bastian: Hard to see which parameters/setups are useful for which topic/variables
- Mad: One broad topics are behavioral interventions, but those are very interesting and 'easy' to do. Not necessarily related to physical well-being but e.g. mood. Some challenges to self-research:
  - Adherence even if you want keep doing something. Plans change while doing the self-research process (and that's not necessarily a bad thing, maybe changing plans is correct)
  - Framing questions, can you teach people this? C.f. SMART questions from Martjin de Groot
- Steven: Currently working on a book on how to do self-research. One thing: Which kind of self-researcher to target, some things have a wider audience while others are following more traditional research methods. Finding out which things can be applied to n=1.
  - For motivation: People need to learn while doing the tracking to sustain motivation. So a format that requires collecting baseline, A, B, and only gets "learning" after a significant period commonly breaks down (difficulty with adhering to this plan)
  - Learning how to do the project takes some time before methods become somewhat standardized, need to try some things for that. Keeping track of this process would be valuable
  - Writing out things that you think might effect your outcome is valuable
    - (a sort of pre-registration recording what you thought you knew beforehand, to compare with later to see if you learned anything)
- Bastian: seeing examples of what others have done and how they did it not just the final product, but also the process they took to get there
  - Steven: the results don't transfer individual to individual but methods often do
- Michael: there's a tension between science (which depends on reproducibility) and art (which emphasizes uniqueness)
- Steven: thinking about moments of reflection, when do you reflect on results. the act of sharing what one learned with others can help people consolidate what they learned.
- Richard: there are a lot of people that have done similar things would love to see a bibliography / collection of these
- Bastian: Paris has switched back to curfew & curfew + lockdown, wanted to see if there's a difference in the data
  - can see noise level means go down in evening as expected. This remains true even during midnight to 6am, which I found surprising.
- Michael: curious about personal data/information management solutions. tool people might be interested in is "tinderbox" method for taking notes, analyzing data
  - curious about if there's any research/understanding about what motivates people to use personal data management tools
  - Contact him at Michael@identitypraxis.com

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## November 05 (Self-research chat)

10:00 PDT / 13:00 EDT / 17:00 BST / 19:00 CEST

Zoom videochat link: <a href="https://zoom.us/j/196519106">https://zoom.us/j/196519106</a> Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/y5ztlnvh">https://tinyurl.com/y5ztlnvh</a>

#### Attendees:

- Bastian Greshake Tzovaras
- Enric Senabre
- Katarzyna Wac
- Gary Wolf
- Mad Ball
- Abhik Chowdhury
- Steven Jonas
- David Blackwell <a href="https://my.pgp-hms.org/profile/huFE0257">https://my.pgp-hms.org/profile/huFE0257</a> Atrial Fibrillation, Eliquis, CPAP, B12, D3, Zinc, B1 Thiamine.
- Add yourself here

#### Topics:

- Bastian: no updates, been busy with work research
- Kate: RHR went down so nicely since moving to Geneva, but now up with the lockdown
- Gary: Update on Arrhythmia project, can show something
- Steven: Update on using suppl. Oxygen during sleep
- Abhik: no updates
- Mad: continue doing mood tracking, but no update yet
- Enric: working on customizing daylio, but adapting project to lockdown circumstances: sleep
- Dave: Afib study has turned into b1-thiamine study, B1 seems to be curing me of my Afib, making my neuropathy better, makes me wake up earlier; will continue to monitor my energy and focus levels which I hope will continue to improve after the first remarkable improvement in late September. Why did my B1 level go low? Overuse of B12 from my gene CTH variant high homocysteine?

#### Notes:

#### - Steven

- Post on reddit pointing to study that suppl. Oxygen (w/ oxygen concentrator) during sleep improves symptoms of depression
- tried it out, intention to try every night in october. Experience: more intense dreams during the time, felt a bit better during first days.
- Kept up for the rest of the month but with everything going on during the month hard to track things
- Waking up in the night and removing oxygen concentrator. Switched from nose cannula to mask
- Take away: it's not that it doesn't work but effect is small relative to other things going on
- Gary: Do you alternate % oxygen?

- Steven: in study they do 30% oxygen, 3 liters per hour. My machine has different settings but both parameters are correlated in the setup.
- Gary: have you tried doing maybe 30m during the day to see if there's an acute effect
  - Steven: I got the machine to try stuff like this, e.g. immediate impact on energy, reaction time, but haven't been systematic, haven't thought of a good experiment and motivated to do that
- Bastian: any plans to try this or similar again at a different/better time?
  - Steven: this was a good opportunity to revisit and get a better understanding of this topic and think about what to do

#### - Gary

- Motivating to be able to share the project
- Purpose for this phase of matching 1-button-data with zio data is
  - to better collaborate with cardiologist, without having to continue paying for zio sessions
  - Take care of nagging concerns about own data tracking protocol. Screws with motivation if you're not sure you're collecting in the 'right' way. Feeling that i'm actually measuring something, but wanting to make sure
- Luckily one chart in Zio PDF report (30+ pages) has actual calendar with the data
- Compare Zio data (% missed beats in day) to one-button-data (# of presses per day)
  - Normalized data by scaling to worst day in each data set
  - Do correlation between both values
  - Correlation gets bad when taking worst days into account
  - Two ways that methods differ:
    - Fidelity with Ibutton doesn't work too well for the highest range. One-button accurate in a given range, but if too many events it becomes noisy. Zio can still differentiate between "bad" and "very bad" episodes
  - Abhik: How to handle those data with your cardiologist?
    - Gary: Those thresholds for treatment are a mess underneath the neat categories. They would be valuable if you are consistently within a given % category then you might fit it, but as it changes in periods you might fade in/out of the window
- Dave: curious about eloquis or other antithrombotics, if those might be important as irregular heartbeat can be associated with clots forming.
  - Gary: on low dose aspirin, sounds like something to learn more about, look into
- Bastian: these look like good correlations, you can have more confidence in the 1-button data. It might be nice to somehow split the zio night data out, to see if that explains the discrepancy
  - Gary: not sure if it's possible, but maybe I should try to look into how to get more data from the Zio
  - Gary: when I stay up late at night, I'm logging more button presses at night
- Gary: the next step after building confidence is to try some interventions
  - Tried cutting caffeine consumption by 2/3, I think it's having some effect but I'm not sure. I expect to have a "tinkering" process, would love to get below 10 1-button events per day
  - Dave: my personal experience and with family is having to cut caffeine entirely, I think I became more sensitive to it over time
  - Steven: what other things are you thinking about studying?
    - Gary: one thing: sleep, the less i sleep the more events I think. Sports is another
      one. During workouts there are more events but it feels that it reduces the
      episode frequency after. Started taking Vitamin D supplements, one of those
      things

- Steven: While tinkering might want to write out all the things you think about the phenomenon, laying out mental model of the process
- Gary: trying to filter out the night data, the bars are hourly... might be able to determine what fraction are during the day
  - Gary: I think I'm probably just going to call the correlation phase done. I'm not concerned about accuracy on bad vs. very bad days, I want to avoid all of them.
- Kat: I'm interested in what happened after this data, since it was getting worse by the end
  - Gary: there's some interesting stuff going on with long term patterns, maybe I can talk more about next time. I think maybe there's feedback dynamics... one bad day makes the next day more likely to be bad, until breaking out of that "feedback loop" pattern
  - Gary: I have a beta blocker prescription, and recommended to taking it every morning. But maybe what I could try is six days of beta blocker as an intervention, see if that breaks out of a bad phase

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## October 29 (Self-research chat)

10:00 PDT / 13:00 EDT / 17:00 BST / 18:00 CEST

Zoom videochat link: <a href="https://zoom.us/j/196519106">https://zoom.us/j/196519106</a> Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/y5ztlnvh">https://tinyurl.com/y5ztlnvh</a>

#### Attendees:

- Add your name below
- Bastian Greshake Tzovaras
- James Littlejohn
- Enric Senabre
- Gary Wolf
- Steven Kaye
- Abhik Chowdhury
- Paula Leonova

#### Topics:

- Bastian: Reading before sleep, wants to n=1 reproduce the people's trial
- Enric: Experimenting with Fitbit, wanting to try effects of CBD on sleep during lockdown
- Gary: new phase of arryth tracking, got Zeo data, small update
- Steven: food effect study, MSG still weird, doing follow up tests, also testing other "low carb foods", dayjob now working on diagnostics, hoping to do at home testing
- Abhik: Got a bunch of IoT devices (withings devices: sleep pad, scale, blood pressure). Excited to compare respiratory rate measures
- Dave:
- James: research on hay fever, update: wanting to present some days worth of data

- James:
  - spikes of hay fever symptoms, looking at heart rate for the day after those spikes
  - HR data shows that on days with symptoms also having higher HR (also related to movement) but little activity the day after
  - Ideas for how to analyze?
    - Abhik: do you have control data?
    - J: yes, many years of data
    - B: could look at resting heart rate to see how it compares during good/bad days. Or take 'all' heart rate data and correct for activity
  - Gary: How are you doing this? What's the coding environment?
    - J: Vue.js + chart.js
  - Gary: What's the time resolution of your questions? Maybe your question wouldn't need high resolution if it's day-scale?
    - J: wanting to explore it
- Gary:
  - on border zone of personal science & biomedical research
  - collaborate with cardiologist
  - looking at the one-button press data, some periodicity in it
    - suspect it to be due to positive feedback loops of arrhyt.

- Do the measurements of the Zeo patch roughly correlate with the button presses (some offset would be natural, but time of day/day-to-day level?)
- Zeo comes with a button that you need to press when having symptoms, but the button doesn't work too well, no tactile feedback after first button press, led to loss of confidence in the device
- Presses supposed to go along with logging data on phone app
- Zeo filtered the data based on when the button of Zeo was pressed
- Doctor doesn't care much about any of those data, except for whether my reports go along with the actual data from the device
- Doctor found no recordings of false positives: Every time the button is pressed there's an actual incident
- Main thing doctor cares about: Percentage of time in which premature ventricular contractions happen. Metric is done "# of PVCs / # of all heart beats"
- Next step: Putting # of PVC per hour into spreadsheet alongside the one-button presses
- Enric: the zeo also counts during the night when you sleep
  - G: I expect the Zeo to overcount, its very sensitive but the button presses might miss when it's not too bad
- Bastian: Also a function of the clustering of PVCs
- James: What's the reasoning for the banding in different percentages?
  - G: measured by outcomes to create those slices. People with <10% are unlikely to suffer sudden cardiac death. Even if the heart surgery isn't very invasive, since people are unlikely to die with <10% of PVCs so preferable to not perform surgery
- Steven:
  - Exploring supplement effect. Base is Ketochow + Butter
    - w/o insulin spikes by 30 mg/dL,
  - Adding MSG adds another 30 mg/dL
  - But no additional effect when adding normal dose of Insulin
  - MSG by itself doesn't lead to peak either
  - Posted observation on reddit etc.
    - thoughts that MSG might stimulate sugar release from liver or other interaction effect with fat
  - next step: MSG + Butter to see if that has a effect and do dose-dependant studies as currently large dose of MSG
  - Dave: Why adding MSG?
    - S: MSG has been reported to actually lower blood glucose + stimulate insulin production, but all done with high carb meals and non-diabetics. So wanting to explore how it goes with low carb diet and having diabetes
  - Gary: How much MSG?
    - S: I tried 10 grams, it's the upper limit of what has been demonstrated to be safe

## October 22 (Self-research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/j/196519106 Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/y5ztlnvh">https://tinyurl.com/y5ztlnvh</a>

#### Attendees:

- Add your name below!
- Bastian Greshake Tzovaras
- DC
- Enric Senabre
- Sarah Lamb
- David Blackwell <a href="https://my.pgp-hms.org/profile/huFE0257">https://my.pgp-hms.org/profile/huFE0257</a> Atrial Fibrillation Eliquis CPAP B12, D3, Zinc
- R Sterling Snead
- Richard Sprague (joined super-late, sorry!)

#### **Topics**

- Reminder: Europe switches from daylight saving to standard time on Sunday, so the self-research chat on the 29th will be an hour earlier for Europeans!
- Bastian: Still interested in blood glucose spikes late in the evening, but haven't gotten around to start experimenting yet
- Enric: New to self-research, but interested in the influence of the environment on mood
- DG: Researching chess as an option for cognitive testing, might include transfer learning to math, needs to find AI analyst to split chess into metrics
- Sarah: First call! Tracking health through fitbit, lots of analysis of stress levels due to home office
- R Sterling Snead: working on the github for personal data,

- R Sterling Snead:
  - Github for personal data, covid app as proof of concept
  - Issues around ethics: system should work for children, people come of age at different ages in different countries
  - High barriers of entry: how do we bring these tools to less technical people
  - Data access issues: example of how hard it is to even get a copy of x-ray images
- E
- Please join the Seattle Quantified Self Meetup on Thursday October 29th at 6pm PST
  - https://www.meetup.com/Quantified-Self-Seattle/events/274086876/
  - We are preparing updates on glucose tracking, heart rate, and more.

## October 15 (Self-research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/j/196519106 Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/y5ztlnvh">https://tinyurl.com/y5ztlnvh</a>

#### Attendees:

- Add your name below!
- Bastian Greshake Tzovaras
- Paula Leonova

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#### **Topics**

- Bastian: Small glucose monitoring thing
- Steven: Effect of MSG, saw huge increase when eating in meal, but no effect in normal meal
- Paula: tracking when studying, discussed last time to see different search terms

#### Notes:

- Bastian: Glucose tracking effect before sleep, also applied to Gary
  - Steven: Can be protein which kicks in later
- Paula:
  - Friends bullet calendar model: http://www.linacolucci.com/2020/09/fruit-stand-method/
  - Good discussion on statistical tools (with mention about using lags): https://forum.quantifiedself.com/t/what-statistical-tests-could-i-play-around-with/8320
  - A blogpost about data diaries done as part of a course:
    <a href="https://medium.com/notes-from-the-classroom/creating-data-diaries-as-a-class-exercise-to-u">https://medium.com/notes-from-the-classroom/creating-data-diaries-as-a-class-exercise-to-u</a>
    <a href="https://medium.com/notes-from-the-classroom/creating-data-diaries-as-a-class-exercise-to-u">https://medium.com/notes-from-the-classroom/creating-data-diaries-as-a-classroom/creating-data-diaries-as-a-classroom/creating-data-diaries-as-a-classroom/creating-data-diaries-as-a-classroom/creating-data-diaries-as-a-classroom/creating-data-diaries-as-a-classroom/creating-data-diaries-as-a-classroom/creating-data-di

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## October 11 (Community Call – mostly skipped)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: <a href="https://zoom.us/i/196519106">https://zoom.us/i/196519106</a> Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/y5ztlnvh">https://tinyurl.com/y5ztlnvh</a>

#### Attendees:

- Add your name below!
- Mad Ball
- Gary Wolf
- DG
- Dave

- No plan or announcement was made for this meeting, and no plan to record.
- The zoom room was opened in case anyone showed up for discussion, etc.

## October 8 (Self-research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: <a href="https://zoom.us/j/196519106">https://zoom.us/j/196519106</a> Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/ya6pu3nv">https://tinyurl.com/ya6pu3nv</a>

#### Attendees:

- Add your name below!
- Bastian Greshake Tzovaras
- Enric Senabre
- James Littlejohn
- Gary Wolf
- Steven Jonas
- D G

#### Topics:

- Go around
  - Add your wish to give an update
  - Bastian: Freestyle Libre observations
  - Gary: Some updates on on-going project
  - James: Closed hayfever project, still crunching numbers, having a cold, confusing to switch from hayfever sneeze to cold sneeze
  - Enric: testing different mood tracking apps, probably sticking with daylio

- Notes go here
  - Bringing back the idea of the journal club? For replication to some level... Papers / studies on:
    - Sleep?
    - Diet?
    - Cholesterol?
  - Gary
    - Tracking simultaneously with one-button and the Zeo ECG sensor
      - Zeo app very similar to also tracking observations like the one-button
      - Problem with the app, very inconvenient:
        - Update in the middle of the process, lost some data
        - Abandoned app and only tracking with one-button
      - Whole zeo process clearly not tested with actual users (unclear how to classify events)
    - Ultimately looking for triggers
  - Enric
    - Getting used to daylio and testing the app
    - Can customize things being asked for

- Not a fan of the 5 point rating provided for mood
- Bastian
  - Observing weird blood glucose peaks late in the evening/before bed, seem unprovoked as not in response to food or physical activity. Any ideas where those are from?
  - Gary: I've seen similar effects, people said might be a problem of laying on the sensor
    - Weight on sensor usually drops readings according to the internet
  - Will monitor more closely and try to collect data on food etc. to see if there's anything interesting
- Doing a journal club of papers that might be interesting to use in QS 'reproductions' of findings, testing them, maybe even as a group of people
  - Bastian will start a thread in the forum/link to slack and distribute with goal of finding papers that might be interesting for that

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## October 1 (Self-research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/j/196519106 Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/ya6pu3nv">https://tinyurl.com/ya6pu3nv</a>

#### Attendees:

- Add vour name below!
- Bastian Greshake Tzovaras
- Herman de Vries
- Steven Kaye
- DG
- Gary Wolf
- David Blackwell <a href="https://my.pgp-hms.org/profile/huFE0257">https://my.pgp-hms.org/profile/huFE0257</a> Atrial Fibrillation Eliquis CPAP B12, D3, Zinc
- Abhik Chowdhury
- Katarzyna Wac

#### Agenda

- Go around
  - Bastian: started using the Freestyle Libre v2 sensor
  - Gary: Short update on arrhythmia tracking
  - Steven: starting to test meals, found big impact of two table spoons of butter
  - D G: Looking for a chess coach to quantify mental performance
  - Herman: Shared code for analysis presented last wek
  - Abhik: small eeg recording update, and looking into long term video recording around the house and am setting up my network and storage

- Gary
  - Got a Zio patch, rather large patch worn on chest
  - Worn for 2 weeks before mailing it back
  - Has button that you're supposed to press when experiencing symptoms
    - No feedback, unclear whether it worked or not
  - Log button presses in notebook,
    - only has 20 pages, often experiences 20 events in a day
  - Also comes with apps for tracking events, gives notes field to take notes
  - Warns about calling 911
  - Waiting to see data that comes back after mailing it back
  - Events seem influenced by eating, QS forum member says that HR monitor alerts come before CGM alerts come out (effect of blood sugar on HR)
  - Steven: Well established connection between cortisol & blood sugar. Things related to your heart might trigger blood sugar triggering. Would probably not show up for people w/o diabetes, but might in diabetics
  - Gary: So it's the heart driving blood glucose, not vice versa

- Bastian: do you need a prescription to get one?
- Gary: they presented some years ago at QS conference, were unclear what to use the device for, now went fully into medical. You need prescription, it's expensive.
- Herman: How often do these arrythmias happen?
- Gary: It's interesting to me: biomedicine defines treatment on frequency, if it's rare you don't treat. If it's more frequent you take drugs. If more than 2% of time you can access surgery

#### - Steven K

- Started testing meals, small amounts of butter delays glucose impact by 30-40 minutes
- People talk about that but never saw that in medication doses
- Standardizing with

#### - DG:

- Hoping to get a large number of metrics from chess

#### - Herman:

- Did HRV analysis from Oura data:
  <a href="https://hermandevries.nl/2020/09/23/relationships-between-hrv-sleep-and-physical-activity-in-personal-data/">https://hermandevries.nl/2020/09/23/relationships-between-hrv-sleep-and-physical-activity-in-personal-data/</a>
- Bastian converted it into a notebook: <a href="https://exploratory.openhumans.org/notebook/165/">https://exploratory.openhumans.org/notebook/165/</a>

#### - Abhik

- Started playing with the Muse S that's designed to be worn during sleep
- Discovered the "Mind Monitor" phone app to stream data, does visualization of data and can export
- Also set up a couple of cameras around the house that record with raspberry pis. I joined the sub-reddit /r/datahoarders but maybe folks have ideas for storing data?

#### - Steven J

- Idea for a new project: interested in the use of supplemental oxygen and it's effects.
- Recent study: https://www.mdedge.com/psychiatry/article/228951/depression/breathing-enriched-oxygen-improves-major-depression
  - Had people on oxygen concentrators during sleep. Found that people that received oxygen improved in terms of symptoms from depression.
- Has all tools needed, interested in giving it a try
- Herman: Did you test O2 saturation?
- Steven: gave it a try, but didn't record any data

## September 24 (Self-research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/j/196519106 Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/ya6pu3nv">https://tinyurl.com/ya6pu3nv</a>

#### Attendees:

- Add your name below!
- Bastian Greshake Tzovaras
- Enric Senabre
- Richard Sprague
- Steven Kaye
- Herman de Vries
- D G
- James Littlejohn
- Katarzyna Wac
- Gary Wolf
- •

#### **Notes:**

#### Go around:

- Bastian: not doing any self-research project
- Enric: Interested in a project on effect of natural vs. built environment on mood
- Gary: Have a small update to share later
- Herman: Did an analysis on Oura ring data
- Kate: tracking resting heart rate, no update
- Steven: Impact of food ingredients on blood glucose, tested citric acid recently, interested in feedback on how to work with collaborators on this
- James: tracked hay fever, hopes that the season ends soon
- Dimitri: No updates
- Richard: interest in CGM & microbiome, did experiments with new app from UCL, will tell about it (includes test with dried blood spots for blood fat)

#### Updates:

#### - Gary

- One-button tracker for cardiac arythmia
- Accidentally sent the one-button through the washer & dryer, still works though, maybe because of the dryer?
- James: wondering how people handle changing devices to join data later on
- Gary: assumption of continuous data are one major reason why experiments fail, easy to get lost. This project is tolerant for this failure as it's single column of data and observational
- Bastian: it's a hard problem, i switched devices so much over 8 years and it's not easy to correctly merge it
- Dimitri: any tools for merging different data that could be done on open humans?
- Bastian: we wanted this for a long while, but it's just so hard

- Steven: Having similar issues at his day job. Ended up defining standard data format and write code "Formatter" to standardize the data into this format. Now just need to add the formatter for any new instrument.
- Gary: requires a lot of maintenance, but not impossible
- Richard: typical problem in health field, people develop standards to solve this (e.g. FHIR?). End up spending a lot of time creating those standardizers
  - FHIR is also known as HL7: <u>https://en.wikipedia.org/wiki/Fast\_Healthcare\_Interoperability\_Resources</u>
  - <a href="https://www.carecloud.com/continuum/what-is-fhir-fast-healthcare-interoperability-resources/">https://www.carecloud.com/continuum/what-is-fhir-fast-healthcare-interoperability-resources/</a>
- Gary: the community has a lot of domain knowledge that could define an ontology as described by DG.

#### - Steven

- Food-effect study lead to one more person that wants to join efforts
- Trying to work out the shared protocol, challenge I had last time was how to make sure that participants are doing the protocol consistently enough to allow data comparison (lots of variables like time of day, device use)
- **Kate**: Protocol everything, instructions for everything. Did study on sleep deprivation, used devices as proof with passively monitoring, otherwise honestly reporting by participants, allow open ended notes to explain weirdness in the data
- **Richard**: Worked on a website for people to upload their abbott freestyle libre data along with meta data for a database to allow comparing data. Especially interested in links to microbiome and how it changes response. See <u>CGM Hackers Guide</u> for details.
- **Steven**: Abbott data can't be calibrated internally, so need to calibrate externally. Becomes pretty accurate if you do it. Offsets and gains are dependent on sensor.
- **Gary**: there might be some advice, but it depends on what you want to do. Depends on the type of person you want to collaborate with. We had experienced QS community members, wouldn't have worked without them. Try to find mainly highly engaged people to participate
- James: Embrace the chaos, links to <a href="https://www.cognitive-edge.com/our-people/dave-snowden/">https://www.cognitive-edge.com/our-people/dave-snowden/</a> complex systems ie. a human can not be understood with measurement, is the logic put forward by complexity science. They find human inputs to aggregate the information to make decisions or changes around. An emerging field to keep tabs on I feel.

#### - Herman

- Blog post:

https://hermandevries.nl/2020/09/23/relationships-between-hrv-sleep-and-physical-activity-in-personal-data/

- Working on employee resilience and modeling it for automatic interventions
  - Long-term effects of stress f

## September 17 (Self-research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: <a href="https://zoom.us/j/196519106">https://zoom.us/j/196519106</a> Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/ya6pu3nv">https://tinyurl.com/ya6pu3nv</a>

#### Attendees:

- Add your name below!
- Mad Ball
- Steven Jonas
- Steven Kaye
- Gary Wolf
- Bastian Greshake Tzovaras
- Dave Blackwell
- Katarzyna Wac (Kat)
- Enric Senabre

- Go around
  - o Mad still tracking mood, no update, too busy
  - Steven Jonas tracking alertness, a couple small updates, some screenshare
  - Bastian no updates, busy with new team. if time to talk, we had a journal club ft heyen paper, maybe discuss idea of QS / self-research journal club
  - o Dave tracking blood pressure & heart rate
  - Steven Kaye mostly self-research re diabetes; been on pause working on covid project & trying to get back into things, just published write up. started looking at a bunch of common supplements claimed to impact blood sugar.
  - Gary been on multiweek hiatus between pandemic, fires/smoke, schools, been tracking
     PVCs (heart arrhythmias I could diagnose with self-tracking); moving into another phase but nothing to share today
  - Enric still considering self-research interested in mood influence of urban environment, still reading literature, finding it hard to formalize in methodological way. plant in apartment? how do I influence plants?
  - Kat still tracking RHR which has changed dramatically; would like to update on the withings watch, just a bit
- Steven Jonas trying to test reaction time hourly but was having trouble with adherence
  - o compliance this past week was a lot better
    - what I did was instead of rolling hourly reminder, thought it terms of hourly buckets –
       try to do the test sometime during an hourly block
    - used iOS tasks/reminders, set up tasks for every hour of the day guessing compliance went from 5-10% to 75-80%

- o another thing; from conversation, I was reminded that a key component of projects is to have "expectations" so I went through and wrote down my expectations (screen shared)
  - basically writing out my mental model of what influences reaction times
  - I really like this method, planning to do this for projects going forward, seemed like a helpful step for figuring out what I'll learn
- Steven Kaye expectations seems really key; analogous seems to be like "registering your hypothesis" – prevents the "garden of forking paths", making it less likely that you'll create a false conclusion
- Bastian do you find your expectations have been shaped by looking into the data you've collected so far?
  - Steven Jonas not so much, but maybe a function of the tool where I don't see the data easily
- Steven Kaye was studying effect of different foods on blood sugar; finally finished the analysis and write it up
  - o didn't test as many as I'd wanted but what I did was pretty interesting
  - o calculated peak glucose and "incremental area under the curve" (IAUC) that's the aggregate effect on blood sugar
  - o macronutrients pretty much as expected
    - observation on fat: no impact whatsoever, even though some people report they need to dose based on fat
  - o fiber: insoluble fiber is *supposed* to be just not digestible. and this just was not true.
    - oat fiber, not digested, as advertised
    - resistent wheat starch was almost like other carbs! 76% of IAUC compared to glucose
    - inulin in between
    - Mad asked in forums whether this might vary person to person, and I'm super curious about that. would need someone to do the experiment.
      - Mad: what type of person would you need? someone with diabetes? non-diabetics?
      - Steven: diabetics are more sensitive to seeing effects, so non-diabetics might be able to contribute... but they would need to eat a \*lot\* more to see the effects. So I had to eat 50g inulin which is already a lot... they might need to eat 200-300g of inulin, which would be pretty challenging.
      - Bastian: do you think some of the current classification is due to testing with non-diabetics?
      - Steven: this seems likely, yeah
      - Gary: maybe some of it is from testing in animals?
      - Steven: probably there isn't relying on animals since their digestion is very different (e.g. a cow can digest cellulose)
      - Steven: I did get one person with TID that asked if she could try it too, see if it replicates
    - Non-nutritive sweeteners didn't impact blood sugar
    - Combining ingredients so far not seeing effect but not much tested here
  - one frustration is that my baseline data is now out of date, medications and diet has changed over past months, so to start collecting new data I need to recollect baseline data
  - one thing I learned was that it was an enormous amount of work to get clean data. would have to fast a lot, skip breakfast, eat the ingredient at lunch & measure from there, and can't eat "real food" until the blood glucose goes back down
    - that regimen was quite difficult.
    - less difficult with "does it have an effect or not?" because I'm not worrying about accuracy of that, just need to do it once or twice
    - Bastian the question about "is it really low carb" is really interesting

- Bastian and the regimen is annoying, I remember waiting for my blood sugar to go back down so I could go eat real food
- o Enric: do you have a link to share? so I could share with others that might contribute
  - https://www.quantifieddiabetes.com/
  - Final write up here: https://www.quantifieddiabetes.com/2020/09/measuring-effect-of-low-carb.html
- Mad: it's striking how much discussion we have around "low carb diets" but we might not be talking about the same things, one person's effort might be full of stuff that's actually digested and impacting blood sugar vs. another that's not eating those things, it's muddying the whole discussion
  - Steven Kaye: one thing I didn't bother testing is maltose, which basically has 50% impact on blood sugar
- Steven Jonas: have heard about eating late having longer effects increasing blood sugar,
   sleep affecting the blood sugar impact
  - Steven Kaye: I find that too; when sleeping, body flushes insulin from blood, preventing it from going too low during a time where you aren't eating. So if I want to have a big meal, either at lunch or otherwise early enough
- Gary: did you control for your activity at all? some projects have shown a blood glucose elevating impact of activity.
  - Steven Kaye: yes; the type of exercise impacts if up/down; all of these were taken on
     \*non\* exercise days. one of the first posts was about the exercise effect.

#### • Journal club?

- Steven Jonas I like this idea... I know a lot of self-trackers are inspired by research. Was thinking about
  - beyond inspiration, training people on how to read the research and convey it to others
- Steven Kaye I've done journal clubs and what works well is each week one person takes the role of presenter, presents on it with slides & discussion questions, often doing it over lunch
- Steven Jonas wonder about ideal length
  - Steven Kaye we always did 30-45 minutes ... a bunch of scientists talking about papers in their field
  - Bastian the ones we did when I was doing my phd, people did a whiteboard talk for 15m, forcing them to summarize the paper on the board (preventing copy/paste figures)
- Kat Withings ScanWatch update by student (Alexandre de Masi).
  - Good news is that Withings Moves gives ecg raw data in CSV regarding!
  - o Looking at heartbeat data, can derive e.g. peak to peak measurements
  - Student (?) has created a notebook analyzing it, can see information about distribution of the peaks
  - Gary one of the things I wonder about that's produced by Zio is "time in arrhythmia" (what is that?)
    - Kat there's some decision making processes to get something that high level
    - Gary I get the feeling that there's domain expertise that we all lack
    - Steven Kaye wonder if the cardiology groups that Apple partnered with might have students / academics that might be interested
  - RAW file + processed file shared on slack #selfresearch channel
- Mad: On journal club it isn't necessarily academic papers, it could be discussing a write-up or show&tell talk
  - Steven Jonas or books, yeah. But also, partly wanting to help demystify academic papers so people are more able to read them.
    - Since folks seem interested here in the idea maybe that's motivation to pursue it:)



### September 10 (Self-research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/j/196519106 Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/ya6pu3nv">https://tinyurl.com/ya6pu3nv</a>

#### Attendees:

- Add your name below!
- Mad Ball
- D G
- Gary Wolf
- Bastian Greshake Tzovaras
- Steven Jonas
- Katarzyna Wac
- James Littlejohn
- Enric Senabre Hidalgo
- Abhik Chowdhury

- Go around
  - Mad nothing in my personal project (mood tracking) to update, but something to discuss about the chats in general
  - o Gary maybe small update on arrhythmia project
  - Steven no update on reaction time tracking, having difficulty doing the tracking, if time maybe talk about tips and tools
  - Kat tracking resting heart rate, significant difference since move to Geneva but no insight/update
  - o Bastian no updates, been swamped with meetings
  - Enric been working on <u>a doc</u> to organize the idea of urban VS natural environment affects me, exploring mood tools, potential 'interventions"
  - o James topic was hayfever, I do have a little update on that
  - o DG record typing and? speeds and other stuff
  - o Abhik getting into tracking lots of
- Meta interested in doing a more formal research project & publication about these meetings & general aspects of collaboration in personal science / self research
  - Steven this sounds exciting to me, peer learning environments are something I'm really interesting to me. with show&tell hoping it helps people, and peer learning rather than "from experts"
  - o James thinking about collective intelligence
  - o Kat would love to be involved and contribute
  - Mad: Q about whether we are okay with private recordings for the purpose of this research study
    - answer on recording ok ... private recordings, avoid cloud storage
    - Steven I know it'll still affect what I say but am ok with doing it but I know it'll still affect what I say & expect it to go back to unrecorded

- Enric should think about this, because it can affect how people do things, and it's not really necessary to collect information and can be disruptive to the community conversation. would prefer to put it on hold, could be more negative.
- Happy to share the IRB submission
- Gary was hoping to use zio arrhythmia patch to compare against own perception with one-tracker
  - went through a period without much symptoms and decided it didn't matter much, but past few days had more... so I think I'll go ahead and get the Zio
  - o unfortunately data I get is just a pdf, no access to digital / data itself
  - Mad: sucks to not have data access... almost makes one wonder if one can extract it from graphs
    - Gary: the determination of an arrhythmia event is fuzzy/unclear, so they're training a model to match expert opinion but it's likely that even if I got raw data it wouldn't be interpretable
  - Kat curious if there was there some sort of context change that might have caused the change in symptoms? could be a lot of things, even weather
    - Gary it's an interesting question... my design has been very observational, I'm very curious about
    - Kat I mean that maybe \*you\* had a different rate of sensing events, less sensitive
      - Gary I feel I became more confident, in the first phase I did a lot of calibration by comparing to my monitor. I occasionally check - eg if I detect an episode and spot check, and I always detect it... the question is are there episodes not detected, and I really hope to address that with the Zio
    - Kat have you looked into the new nokia watch that has realtime ecg, you can touch to get this, it's targeting arrhythmias. I haven't looked into data access – will look into it.
      - Bastian is it different from apple watch?
      - Kat I think it's basically the same
      - Bastian noting that the ecg is an exception for data access/export, the only thing you can get out of it is a pdf... maybe some issue with FDA approval, regulatory reasons for only a report
    - Gary if I could even find some approximate accuracy, good vs bad days, I don't care about specific
- D typing speeds, and anki scores (intelligence/thinking)
  - o also movement using ambient labs and raw accelometry data
  - o mostly worked on data flow network for getting data from these various sources

- o at one point noticed typing speed drop significantly
- o Gary: what is the data flow network
  - D: I've been graphing the data flow with a network graph, interaction network of different data sources
    - directed graph -- blues are apps & devices, orange aggregators, green sensors
  - Kat do you need a list of sensors? I saw a list of 438 sensors, if you're interested
    - List of the sensors/devices <a href="https://doi.org/10.6084/m9.figshare.9702122">https://doi.org/10.6084/m9.figshare.9702122</a>
- Steven: how long have you been using Anki, what using it for
  - D: vocabulary/languages, trying to use for statistics but that hasn't been working well
  - Bastian: hard to break down to small enough chunks? D: yeah also it's not just memorization... Steven: yeah, learning to break knowledge down to flashcards is tough
- Mad: curious about the network graph, what sorts of things have you learned or are looking to learn?
  - D: best devices to buy, e.g. if there's two devices that jointly cover all data, would want to get those

- Bastian: also seems nice to learn what chain of tools will get data from X to Y to Z
- D: also... understanding how what you're measuring with the sensors compare
- James unanticipated, second phase of the hayfever season
  - actually recorded illness symptoms but a few days later realized hayfever symptoms,
     especially because a family member said they were having symptoms, realized it was actually
     a resurgence of hayfever (very unusual to have this in my experience)
  - o raises a question, how do you know when you're actually sick
  - Mad reminds me of situation with my kid getting fevers, but I notice nobody \*else\* getting sick – I started tracking fevers for the whole family - which has prompted me to interpret his symptoms differently, wondering if he has a syndrom and \*not\* viruses (waiting to see if it happens again now)
  - Steven reminded of Thomas Blomseth Christiansen has found no correlation between pollen counts and his symptoms
  - Mad why even bother with pollen counts if they don't correlate with symptoms, do they correlate for anyone
- Steven wondering about strategies for collecting data throughout the day, e.g. for me the reaction time, more often than a day, e.g. hourly patterns. and e.g. Mad with mood tracking. And we're both finding it's hard.
  - Wondering what has worked for other people, maybe changing my strategy
  - Mad I don't hold myself to needing to do it on the hour, but (maybe wrong to do this) don't bother. I end up feeling motivated
  - Steven I get notification fatigue... I tried having a random rolling timer of 45 minutes to 1.5 hours, I forget to set the timer in the morning. I'm reminded of a meditation project where I timeboxed where I had to do it sometime in the hour and that worked better
  - Mad do you worry about doing things too close? eg with timeboxing would you worry about doing it at the end of one hour and start of next? Steven: agree that there's reluctance to do it e.g. just 5 minutes later because it's the turn of the hour
  - Enric curious about an app that shows up when unlocking the phone, <u>younlocked</u>
    - Steven it's android only, I've played around with it, it has to be a really simple question so you can do it quickly
    - Bastian I can imagine it disrupts the intended use of the phone, forgetting what I meant to do with the phone
  - Bastian I wonder if notifications would be more helpful if they told you how long it's been since you last did it, instead of just prompting
    - Steven I've used that on top of regular reminders and found it helped to have that in addition to the regular reminders
  - o James I notice the more severe symptoms are the more I track

## September 8 (Community Call – Autistica/Turing CitSci)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/j/196519106 Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/y5ztlnvh">https://tinyurl.com/y5ztlnvh</a>

#### Attendees:

- Add your name below!
- Bastian Greshake Tzovaras
- Mad Ball
- Katharina Kloppenborg
- Georgia Aitkenhead
- Kirstie Whitaker
- Enric Senabre
- Zachary Standig
- Vox Buchanan
- Adi Singhal
- Coral Shuster
- Georgia Aitkenhead
- Jan Taco te Gussinklo
- Katharina Kloppenborg
- Susanne Ibing
- Abhik Chowdhury
- Katarzyna Wac
- Danny Lämmerhirt
- Morgan Hough
- Richard Sprague

### Agenda:

• Learning about the <u>Autistica/Turing Citizen Science project</u>

Community meeting are recorded and posted on YouTube, but feel free to take notes below!

- Autistica video <u>here</u>:
- Here's the get involved page:
   https://alan-turing-institute.github.io/AutisticaCitizenScience/get-involved/
- And Georgia is the best person to email gaitkenhead@turing.ac.uk
- See also the #autistica-turing channel in the Open Humans slack (openhumans.slack.com) you can join this slack using: <a href="https://slackin.openhumans.org">https://slackin.openhumans.org</a>
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## September 3 (Self-research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: <a href="https://zoom.us/j/196519106">https://zoom.us/j/196519106</a> Passcode: 922125

Recurring calendar event: <a href="https://tinyurl.com/ya6pu3nv">https://tinyurl.com/ya6pu3nv</a>

#### Attendees:

- Add your name below!
- Mad Ball
- Adi Singhal
- Katarzyna Wac
- Gary Wolf
- Bastian Greshake Tzovaras
- Enric Senabre Hidalgo
- Abhik Chowdhury

- Go around
  - o Mad brief help Q
  - Kat tracking resting heartrate/wearable, happy to be back
  - o Gary just got back from being away
  - o Abi Q about IRB stuff around self tracking
  - Adi currently coding (labeling), no updates
  - o Bastian tracking updates, no updates
  - o Enric postdoc at CRI, new to self research
  - Paula data scientist in education, track how I self study, using pytorch
- Abhik
  - o IRBs and self research
    - "remembrance agent" and memory augmentation. there's a gossip problem how do you record/talk about someone else that hasn't consented to being recorded
    - other people in his lab were using this and linking them, and raises privacy questions about sharing stuff
    - want to record things I see & hear, it seems problematic because it shares things about the people that are interacting with me
    - so: privacy questions around information I hold as an individual that I might not be the only person affected by
  - Mad: I would first say that this is an ethical question (and not just bioethics) so maybe think it about it
  - o Kat: reflecting on collecting CGM data with Eric Daza
    - we published self-collected data that didn't go through an IRB
    - When we do quality of life assessment there's always going to be information about personal life and interactions with other people, sometimes quite sensitive (e.g. sex life with spouse/partner) and we always anonymize it
    - we tell people to tell us to the level they're comfortable with, to explain phenomena (sleep, stress, etc)
      - IRB also needed to have an IT team review the tech stuff (not IRB itself)

- o Mad: reminds me of research Camille Nebeker has discussed as an ethical issue continuous photo capture wearing a camera.
- Adi: if Abhik is the only one that's doing data analysis and research and not sharing with others – what's the concern? Abhik
- Bastian: rich history of self-experimentation e.g. h pylori causing ulcers and there's someone at CRI that studied bee stings on himself
  - Mad: similarly, from Michelle Meyer: <a href="https://blog.petrieflom.law.harvard.edu/2014/04/04/whose-business-is-it-if-you-want-to-o-induce-a-bee-to-sting-your-penis/">https://blog.petrieflom.law.harvard.edu/2014/04/04/whose-business-is-it-if-you-want-to-o-induce-a-bee-to-sting-your-penis/</a>
    - concludes there's a technical legal "requirement" but people might not feel it's needed, IRBs might not want to review, publishers might not care
    - e.g. Eric Daza & Kat not having an issue with self-collected data
  - counterpoint to this is Sara Rigarre's experience, with papers necessary for her dissertation rejected
- Enric: wonder how it relates to "where you publish" blogpost vs. academic journals
- Enric thinking about buying a wearable, thinking about what is it I want to learn
  - thinking about living in Paris and how that might be affecting my life in comparison to living somewhere more remote. still not having a "research question".
  - o measuring what I experience, how I feel
  - Bastian: Mad's mood tracking might be relevant Mad: I do, but maybe Adi's thought tracking is interesting
    - Adi: I've been using an app that records thoughts and also captures data like location, can take photos. I don't like tracking a scale emotion (1-10) but like to capture more complexity in the emotions. I'm going back over the past data to "code" what emotion they represented, but it's a lot of manual work, have only done 27% of data so far
    - Adi: the advantage of doing after the fact is I don't have to ask myself what I'm feeling. And I already have the habit of logging my thoughts, and the mood tracking becomes a byproduct of that.
  - o Jon Cousins "word stem completion" for mood tracking.
  - Mad: Adi, how hard is it to determine the emotion of what you wrote? if it's hard, if/how/why is that? Adding a single word like "nostalgic" sometimes when it's something more complex or subtle
    - Adi: for the most part determining a mood from the thought has been really easy to do
    - When writing things now I do think about just adding the labels when I do it though, because it's a lot of work to go back over data later! But since I started doing it post-hoc in bulk, if I started doing it live it'd create a difference in the data. Also worry that I'll be too influenced by what I'm currently logging, it might affect what I record.
  - Kat: wondering what nature experience is, what is the "dose" what sort of experience you
    expect to have (few hours? whole weekend?)
    - Enric: imagining environments during the day, shorter "doses" and the effect of built environment. Agree that it's difficult to isolate this as an "experience" and be precise. AT the same time I think this may be a major influence on my mood based on what I remember about myself.
    - Kat: re paper of looking at nature pictures, effects of them, look at what they measured
    - Mad: think about using an "intervention" (test walking in nature-dense area deliberately vs not) A vs. B rather than hope to correlate a complex phenomenon to some complicated data that might be weakly related
      - Bastian: note that it's very hard to do an intervention that just affects one variable e.g. a walk in nature also means you exercise more

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- Abhik: made a jacket with computers on it for collecting and analyzing data for augmentation purposes, and local processing for privacy reasons too
  - Mad: encourage reading about Star Simpson and worry about how people react, worry about what it looks like
  - Abhik: yeah, I think about it a lot, honestly it'd be easier I could just wear this outside but I know how it's going to look to others and have to put in some time to make it look good

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## August 27 (Self-research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/j/196519106

Recurring calendar event: <a href="https://tinyurl.com/ya6pu3nv">https://tinyurl.com/ya6pu3nv</a>

#### Attendees:

- Add your name below!
- Mad Ball
- Paula Leonova
- Steven Jonas
- James Littlejohn
- Bastian Greshake Tzovaras
- Abhik Chowdury
- David Blackwell

- Go around
  - o Mad: no updates...
  - Abhik: did 23andMe health thing, found their provided information interesting, I'm sure there's more to do with that
  - Steven: tracking shaking, updating spreadsheet right now, might be able to share later in the hour. also been experimenting with locking up all my devices from 7pm to 10am (!), can share some of what I've experienced through doing that
  - Paula: no updates, last time's brainstorm helpful, want to pursue looking at different types of sources when I study (per Bastian's suggestion) but still TODO
  - Bastian: no real update; posted on slack an observation from vacation where resting heart rate dropped a lot. would be interested in potential explanations.
  - James: still tracking hay fever, recovered discipline on self-tracking. also interested in potential ideas about posture self-research.
- Abhik: downloaded 600k SNPs Mad: not 1M? Bastian: yeah, they've downscaled with optimized locations.
  - Mad: 23andMe has some SNPs that are rare but medically relevant, but they don't show the results due to FDA limitations, but you can look those up in the raw data. Genevieve uses public databases called Clinvar <a href="https://www.ncbi.nlm.nih.gov/clinvar/">https://www.ncbi.nlm.nih.gov/clinvar/</a> & Gnomad <a href="https://gnomad.broadinstitute.org/">https://gnomad.broadinstitute.org/</a> to interpret the data more: You can see how rare those variants are to interpret how likely it is to have an impact
  - o <a href="http://myvariant.info/">http://myvariant.info/</a> is an API to find out a lot for individual variants that 23andMe tests
  - Bastian: anecdotally, be aware that variants that are very rare are highly likely to be false positives – we've seen that in openSNP data

- you can check for these artifacts in the openSNP data (which is public)
- Genetics of personality type? Mad: won't analyze the genetic data, you can do a personality type test
- Combining multiple genes Mad: I'm really skeptical about combining multiple genes together, they can't be naively combined without context (e.g. 2x risk and 2x risk = 4x overall), it'll be different each time, because these are like different resistors in a circuit board (e.g. metabolic pathway) that link together in different ways.
- James: I think I've been doing a self-research project on posture of many years...
  - working on posture for past 15 years + playing violin much more recently + getting older has resulted in a new round of issues
  - o open to ideas or research people have done themselves
  - Abhik there's posture correctors that remind you about neck position, but aren't meant for long term wear. but there's video analysis tools that can do pose estimation, potentially of interest
    - https://nanonets.com/blog/human-pose-estimation-2d-guide/ first post I found will poke around a bit more
    - https://medium.com/beyondminds/an-overview-of-human-pose-estimation-with-deep-learning-d49eb656739b
    - James they can have practical implementation issues that make them hard to use,
       e.g. side on
  - o James some of this is habits; usually I had swimming and haven't been able to do that
  - o Mad is the goal to test interventions? do you track which postures are working?
    - James can probably infer posture from wearables, interested in using one hand vs. other step counts & asymmetrical data (playing violin)
  - Steven there's been a variety of posture correctors, e.g. lumoback, would buzz you with bad posture. I recall Ernesto using this and the buzzing being really distracting & would take it off. Had someone present at QS18 about a tracker. I've yet to see a show&tell talk about someone learning anything interesting to note that there is a lot of interest in this area, but haven't seen any real projects coming out of them.
    - Steven: I've used a lot of tools for posture. Personal experiences were, Mood seems to be a factor for me. And lower back exercises really seemed to help.
  - o Paula: Curious if there's a relationship between posture / keeping posture and how much sleep you've gotten, how much energy you have → maintaining better posture. Have people compared sleep quality/quantity and posture.
    - James: when I started posture things, I couldn't sleep for three days due to pain.
    - Paula: it seems like there's feedback between them, pain → less sleep → bad posture → pain
- Bastian: wondering about why my resting heart rate went down
  - o Bastian: Maybe calorie deficit? Can try strict diet to see if it causes the same thing
  - Bastian: Wondering if the weather/cold affected how the sensor operated sleeping outdoors
     and that affected the data produced
    - apple watch I have inconsistent data but the data I have seems consistent
    - Paula: maybe correlate weather data to determine the effect of temperature e.g.
       winters in paris Bastian: but I'm sleeping indoors in Paris, very different
  - Bastian: note that I walk a lot in Paris & so don't expect that this was due to a significant change in exercise level
    - Steven: hiking around in iceland seems like it would effect it Bastian: but it was immediate, would expect it to take more time for training to take effect
    - Steven: and with exercise/training wouldn't system be working harder?
  - James: effect of being in nature comes to mind <u>https://journals.sagepub.com/doi/full/10.1177/2164956119848654</u> ?

- o Changed back coincided with outdoor sleeping ending, recovery from hiking
- Steven: trying to frequently test reaction time on hourly basis. Don't have rigorousness on hourly, but trying to do it multiple times in the day
  - o interested in which times of day, trends during the day
  - o reaction time by hour graphed
    - goes up towards 4 or 5pm; ironic because this feels like the best working time
    - outlier at 8pm, probably post meal?
    - Paula: is this averages?
      - Steven: yes, average of all the tests taken at that time. also have count of number of tests at each time.
    - looking at just July data, when I started a focused analysis of the data, see similar pattern
    - reaction time by day, to see "training" effect ... actually reaction time gets "worse" but also note that it's a smaller sample size
      - maybe a correlation/bias in whatever internal trigger exists on "when I do a test" is related to what my reaction time is going to be
    - focusing really intently, I still get long reaction times
  - o Paula: for visualization, I find box plots can be helpful... averages can get skewed by extreme highs and lows, and can give you a feeling for how much variation you see during the day
    - Steven: that's a good suggestion, my goal is to make it really easy to redo update the data and get a fresh analysis right away. Was proficient in excel, been struggling with google sheets to get the same things.
    - Paula: I empathize with struggling to get Google Sheets to do, it can be kind of rigid and frustrating to do the analysis you want in a new tool. A really cool tool is Tableau, and you can have a public account without having to pay for it. It's far more flexible than either google sheets or excel, you might want to try playing with it.
    - Bastian: problem is a bit similar to Mad's mood tracking. By pooling data for each hour, it disregards daily differences... it's almost what you want is differences relative to the daily baseline, maybe there's some way to normalize data per day to the overall measure of the day
  - David: what tool was used for reaction time? Steven: using Vigilance Buddy

### August 20 (Self-research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/j/196519106

Recurring calendar event: https://tinyurl.com/ya6pu3nv

#### Attendees:

- Add your name below!
- Mad Ball
- Aditya (Adi) Singhal
- Dave Blackwell
- James Littlejohn
- Michael Cohn
- Miguel Rochefort

- Adi brief update
  - o used gpt-simple package by max woolf
  - o created "my style of writing" and spat out sample text bits
  - without telling it "make a poem" it \*did\* that! it doesn't make a lot of sense but interesting and a little creepy!
  - o currently seems like it's overtraining
  - Mad: is there training and test data sets? typically that prevents overtraining but, ignore me,
     I'm pretty dated with ML!
- Michael thinking about how to track subjective congnition phenomena
  - o days where I seem to be thinking poorly forgetting, making bad inferences, slowly
    - tried looking at various cognitive tests, and they don't seem to capture what I feel like is going on for me
    - e.g. N-back test
    - Steven uses Vigilance Buddy
  - Mad: do you think about subjective tracking that you can track alongside the objective measures? maybe capture that alongside objective data
  - o Michael going to try out vigilance buddy, see how that works for me
    - David I've noticed focus is a big issue in what I deal with
    - Michael Testing feels like it might not be hard to focus provided motivation, so testing might not be valid because it doesn't have that motivation behind it
  - Mad mood tracking does real time analysis influence current recording of mood?
- Mad brief note on having trouble collecting as much data as I want (target 8+ per day)
  - o Adi how is this set up?
  - Mad iMoodJournal prompts me hourly, but in reality I'm often very busy and remembering to do it when between tasks rather than when prompted. So somehow I have to remember, during those in-between moments.
  - o Group discussion does the analysis confound collection? Or help make collection happen?
    - James it may have a temporary effect that washes out once you have the analysis in place and it's no longer "surprising"

## August 13 (Self-research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/i/196519106

Recurring calendar event: <a href="https://tinyurl.com/ya6pu3nv">https://tinyurl.com/ya6pu3nv</a>

#### Attendees:

- Add your name below!
- Mad Ball
- Gary Wolf
- Paula Leonova
- Aditya (Adi) Singhal
- Steven Jonas
- Abhik Chowdhury

- Go around
  - o Slides Adi, Mad
  - o Brief updates / ideas Steven, Gary
- Adi Narrative-Logging
  - (Q is "narritive-logging" a good name for it?)
  - Using: Journey app
    - can record date/time, location, posture (sitting, walking), weather, image/video/audio, text (can use markdown), tags, mood
  - o Analysis already done:
    - frequency of entries
      - Q: what other stuff to do w/ analyzing frequency of entries?
    - mentions of ex (specific name)
      - interesting to see relationship & break up play out in thought logs
    - word clouds
    - topic modeling with LDA
      - auto-generates topics w/ clustering, can see what words are present in a cluster
    - supervised learning
      - made 16 types of emotion labels for myself
      - coded entries with first, second, third most prevalent emotion about 10%
      - gave these 16 emotions valence and plotting valence
  - Noted correlation between sleeping later & less activity
  - o Looking at location data & where logging occurs mostly in NYU area & hometown.
  - o Tried OCR (Python) to pull additional text data from images captured
  - o Data that hasn't been used:
    - audio/video/images facial recognition? more OCR? audio analysis?
    - my calendar, books read, movies watched
    - Google services (search history, youtube history) & other social media
  - Mad: "Personal Digital Environmental Data": Rescue Time Computer Listening, Streaming service data, search history data, device usage, Calendar data.
  - o Mad: suggestion to think about what "hypotheses" you have, to motivate types of analyses

- Paula: might using this with GPT e.g. GPT2 (GPT3 was just released) examples are giving a
   Twitter feed & the network creates new posts that match the style of previous posts
  - e.g. it can "answer" questions as someone might have
  - You can use the "GPT2 simple" template, feed in text files
- Steven: wondering about Journey "prompts" & what answers you might have answered, predicting how you would answer
- o Gary: NLP expert in the QS Community: Bill Jarrold william.jarrold@gmail.com
- o Paula: For mean comparisons, welch's t-test is common, variances don't need to be the same
- Mad: I wonder if there's patterns e.g. one type of thought (maybe emotion <u>coding</u>) ends up predicting another type of thought later in time
  - Adi: note that I think it's better to be posthoc tagging as I've been doing, rather than in-the-moment
- Abhik: note that machine learning cloud providers have a free tier if you're running into computational limitations on your laptop
  - Adi: I'd have to get the data into the cloud, currently all on my local harddrive
  - Abhik: Maybe subsets of data. But also it might just be easiest to leave a laptop on overnight
- Gary: curious about what benefits you're getting from this analysis/review process. My
  experience is there's an iterative development of workflows based on what I'm learning when
  I review past things
  - reflecting that this is might be thought of as an externalized tool for thinking, helping you think
  - Adi: with review benefits, recently reflecting on the importance of "forgetting", needing to not be using thought processes that \*previously\* worked but aren't as helpful now
  - Steven: when you look at what you wrote in the past, you can see them as a previous person & gives you perspective to see how much you've changed
    - I've noticed that it can be useful to go back to things when you're not in that state anymore. You'll only remember that memory when you're in that bad state but if you remember it when you're in a different state, you have a chance to recontextualize the memory
    - Adi: like rumination 2.0
    - Steven: I've noticed that people that have interesting methods of review tend to get more out of it than time spent on data analysis
      - I had a project where I had a day book, and turned them into flashcards (what did I do that day / exact date). I learned a lot about the nature of memories, and structuring memories, and learned "what was memorable".
    - Steven: always liked the idea of taking lastfm and making monthly mixes, seeing what memories are provoked by that (never did this)
  - Mad: wonder if you could use the coded data to segment things and with GPT create virtual versions of you that are "sad", "happy", "poetic", etc – and whether you can then "talk to yourself"
- Gary brief update, wrapping up arrhythmias project
- Mad brief ask, suggested tools/approaches for learning pandas
  - o Paula data school has good pandas tutorial & videos
- Abhik trying mood logging, but I always answer "okay"
  - Mad I think I try to compare against the previous answer, am I "more okay" or "less okay" and move the answer in that direction ("good" or "so-so")
  - Gary mood is very labile, and deciding, "is this how you're feeling 'right now' or 'over the last hour'"?

- o Steven: some other things to consider
  - <a href="https://www.moodscope.com/">https://www.moodscope.com/</a> can record more than one emotion
  - <a href="http://robinwe.is/explorations/cry.html">http://robinwe.is/explorations/cry.html</a> trying to map out various emotions

## August 6 (Self-research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/i/196519106

Recurring calendar event: <a href="https://tinyurl.com/va6pu3nv">https://tinyurl.com/va6pu3nv</a>

### Attendees:!

Mad Ball

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- Paula Leonova
- James Litttlejohn
- Abhik Chowdhury
- Bastian Greshake Tzovaras
- David Blackwell <a href="https://my.pgp-hms.org/profile/huFE0257">https://my.pgp-hms.org/profile/huFE0257</a> Atrial Fibrillation Eliquis CPAP B12, D3, Zinc

- Paula granular data tracking doing an online course, used rescuetime
  - o hypothesis thought I'd used fewer variety of resource than actually did
  - o noticed: used gmail & finder a fair amount to find things, a "personal project" used to learn on
  - o noticed a lot of "other" that stuff that was a big surprise for me
  - o Bastian: wondering if there's temporal patterns, start with X, then y, then X again
    - Mad: was thinking maybe a lot of "other" have the pattern of  $X \rightarrow google$  search triggered by Q while in  $X \rightarrow$  "other site"  $\rightarrow$  back to X
  - Mad: where are you now, what would you find useful?
    - Paula: I kind of hoped to have a list of resources I found useful... it might help others, would be a motivator to me
    - Bastian: google → other page → if that wasn't used much after that, it wasn't very useful
      - Paula: sometimes a site was super useful, e.g. code I can use right away, I don't need to spend a lot of time on
  - Mad: I do think there's something there, to even just say "look at how much learning I did via going to google, searched for something, and landed on a random website" – sometimes I think it's underappreciated by people how important "web searching" is
    - James: often find myself distinguishing between human error vs. existing/known technical problem the community struggles with
  - Paula: I think the coursework grounds you, it would have been overwhelming to try to learn it from all these other sites
- Mad
  - o Hourly prompt, more frequent tracking
  - Variability score how to convert the data?
  - Bastian one easy thing to do is std dev per day
    - Mad: should I worry about more/less I guess I could deliberately downsample, or bin
- Abhik interested in CGM, connected to mood? attention? focus?

- Paula I think I saw something about blood glucose and athletic performance (I came across this video, but I don't know too much more about it)
- Bastian I did see when hungry blood sugar was low, although when just eating sugar cubes still hungry despite sugar :p
- Abhik also worry about something like juice spikes the data in a way that subtle correlations between glucose / mood
- o Bastian also huge influence of exercise, which diabetics use, greatly changes absorption
- Mad maybe overnight measurements get away from behavior-caused variations, I know morning blood glucose was an overall metric regarding insulin resistance / diabetes
  - Bastian word of warning that freestyle libre has issues if you sleep on it

## August 4 (Community Call – Design/UI/UX of Open Humans)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/i/196519106

Recurring calendar event: <a href="https://tinyurl.com/yamkozvi">https://tinyurl.com/yamkozvi</a>

#### Attendees:

- Add your name below!
- Bastian Greshake Tzovaras
- Mad Ball
- Gary Wolf
- Morgan
- Katharina Kloppenborg
- Abhik Chowdhury
- Aditya Singhal

Agenda: Design/UI/UX: understanding user experience on Open Humans

- Editable by anybody slides about "steps" in joining activity/project: https://docs.google.com/presentation/d/lgdrrjxldS6Takci9TnzkqdO87K4KCFNtVYbDaScLeiQ/edit#slide=id.q8eld6448bc\_0\_15
- Slides from Paula last week, walkthrough of process in joining Quantified Flu last slide has suggested redesign of "joining" <a href="https://docs.google.com/presentation/d/lyjm4A5EJKyWpcdv24fGyejqNnhHnTywkZCpxqRRdTvw/edit#slide=id.g8d21402124\_0\_75">https://docs.google.com/presentation/d/lyjm4A5EJKyWpcdv24fGyejqNnhHnTywkZCpxqRRdTvw/edit#slide=id.g8d21402124\_0\_75</a>

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## July 30 (Self-research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/j/196519106

Recurring calendar event: <a href="https://tinyurl.com/ya6pu3nv">https://tinyurl.com/ya6pu3nv</a>

#### Attendees:

- Add your name below!
- Mad Ball
- Steven Jonas
- Eric Jain
- Bastian Greshake Tzovaras
- Abhik Chowdhury
- Miguel Rochefort

- Mad started hourly tracking and curious about how I should plan to use the data
- Steven starting to collect hourly alertness, want to review setup
- Eric updates on what I've been doing on forum project log
- Bastian can share some data analysis of plume labs device
- Abhik set up some cameras and got muse device various new data collections
- Miguel no updates but have various devices set up
- Eric detailed temperature tracking
  - o detecting subtle changes requires precision... skin temp might not be accurate enough. settled on the kinsa thermometer, can export via text
  - o checking precision a set of measurements are always within 0.1C
  - tested "advice" readings immediately after hot or cold beverages, confirm it takes 20-30 minutes to return to "normal". (unknown: after 20 minutes is it still local to the mouth, or did the whole body temp go up?)
  - tried detailed, hourly measurements. mornings have least variability in general, generally rising later (but also more variable).
  - o lows were outside hiking (even though it wasn't cold) maybe breathing more affecting oral temp. (hard to tell whether it's just oral vs. core temp)
  - o daily measurements, found that low outliers were due to camping, sleeping outside
  - Steven: my kinsa has a "quick read" and "long read" are you using one particular mode? Eric:
     I have the quick care, don't see this setting.
  - Eric: notes the export really sucks, weird text file format and max 14 days. Withings much better, but forehead temp isn't precise enough to detect small changes
- Steven measuring alertness, understanding circadian rhythms and other potential effects
  - curious about:
    - ultradian cycles (less than day but longer than hour)
    - factors sleep, exercise, caffeine, other stimulants (ritalin), environmental temp
      - planning to use nomie to collect these other things
    - is this useful for
  - o using: Vigilance Buddy (iOS) and MultiTimer for reminders, Google Sheets for analysis
    - 1 min test. they recommend at least 2 but I expect 1 min to be a lot better for adherence

- procedure plan was... place phone on flat surface, right index finger to tap
  - turns out this is harder to do sometimes, if I'm out. will sometimes sit on ground, put device on my leg.
- CSV export
- data analysis so far not enough data to say much, but hoping to have a workflow so I can re-analysis pretty quickly
  - adding historical data more data for mornings
- o curious if this is useful for anything beyond "sleep deprivation"
- Mad: curious about "ultradian rhythms" meaning is "less than day, more than hour" how you're thinking about that, not sure current data analysis investigates this
  - Steven: right now have senses and curiousity about it, e.g. around 100 minute patterns and taking breaks, not sure exactly what & hope to learn more by observing
- Abhik: just tried the test and it's hard makes me wonder if the test itself affects alertness!
  - Eric: if you do it repeatedly, wonder how consistent scores are
  - (maybe taking the test more often ithe day changes the overall day's alertness?)
  - Eric: also watching out for initial training effect
    - Steven: what's good is I've already done it ~80 times so hopefully that reduces training effect
  - Abhik: do you get false positives? Steven: pretty rare, maybe just once, so not incorporating these in the analysis
  - Eric: also maybe interesting to check 2m vs 1m tests
  - Eric: another thought is to track meal times. and maybe worth capturing location, whether you're outside, or "not at home". Steven: both are interesting; app does have "location" field I can use.
- Bastian plume labs, version 1
  - o can carry around all day, using since early Feb
  - o plotting before/during/after confinement, NO2 and PM10 which relate to traffic, and can see that air quality is better as expected during confinement, and has stayed down after
  - o Eric: every time I use hand sanitizer VOC goes up
- Abhik set up a bunch of cameras, and in particular curious about how they might be used for passive tracking e.g. when I brush my teeth. long term goal is computer vision.
  - o added illuminators, because cameras were having trouble with "night vision"
  - would love to hear from Miguel about other sensors he's used for passive tracking
  - o imagining being able to do stuff like "notice artifact in one data stream " → "find out what was happening in another data stream"
  - Bastian: have you looked at the EEG because my experience it's mostly artifact
  - Mad: interested to think about what you want to do with, learn from the data. (you mentioned stress)
    - Abhik one thing I'm interested in is feelings of shame, minority experiences, feeling of otherness
    - Mad it can be very idiosyncratic and you might need something that's very contextual and personal for what's relevant to you
    - Abhik it's been interesting to me is what Adi was doing with recording thoughts, is there stuff for people capturing stream of concsicoussness; Steven: there's some tools like this... can't remember offhand, Gary might still be doing it
    - Steven exploring mental/emotional states, tried a bit with muse, didn't get anywhere. also note Jordan Clark's project exploring microaggressions https://quantifiedself.com/show-and-tell/?project=1103

## July 28 (Community Call)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/i/196519106

Recurring calendar event: <a href="https://tinyurl.com/yamkozvj">https://tinyurl.com/yamkozvj</a>

#### Attendees:

- Add your name below!
- Bastian Greshake Tzovaras
- Mad Ball
- Gary Wolf
- Paula Leonova
- Morgen Hough
- David Blackwell <a href="https://my.pgp-hms.org/profile/huFE0257">https://my.pgp-hms.org/profile/huFE0257</a> Atrial Fibrillation Eliquis B12, D3, Zinc

### Agenda:

- QF updates
- What should we work on next with Open Humans? Ideas:
  - Wiki for the OpenHumans
  - Jupyter Notebook integration on main site
  - Bastian: also, finishing DataTypes
    - also, baked in "upload data type" rather than external upload
- Paula: flow notes on QF signupthe schedule for the community calls to monthly and keeping weekly self-research chats? slides:
  - https://docs.google.com/presentation/d/1yim4A5EJKyWpcdv24fGyejqNnhHnTywkZCpxqRRdTvw/edit
- Changing the schedule for community calls?
  - o let's plan for UI session next week (Aug 4) and monthly thereafter
  - o might do Thursday chats biweekly
- Finding some time for a UI session (maybe in one of the community calls?)
  - Elements that users have to understand: hierarchy of resources (OH, QS, Project, Data Added).
  - Should there be a diagram of the system hierarchy or elements that could be presented in some way?
  - Authorization page in particular, which thing to do next (i.e. click)
  - is there a problem with the word authorize? Can there be a clear vocabulary for each element in the hierarchy without overlap?
  - Are Open Humans and QF users the same? Overlapping? Different?

# July 23 (Keating Memorial Show&Tell)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Weekly self-research is replace with a Show&Tell this week!

This form is needed to get the Zoom link: <a href="https://forms.gle/ZHsbxKLsnDFjco4V6">https://forms.gle/ZHsbxKLsnDFjco4V6</a>

## July 21 (Quantified Flu Community Call)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/i/196519106

Recurring calendar event: <a href="https://tinyurl.com/yamkozvi">https://tinyurl.com/yamkozvi</a>

#### Attendees:

- Add your name below!
- Mad Price Ball
- Bastian Greshake Tzovaras
- Gary Wolf
- Morgan Hough
- David Blackwell <a href="https://my.pgp-hms.org/profile/huFE0257">https://my.pgp-hms.org/profile/huFE0257</a> Atrial Fibrillation Eliquis B12, D3, Zinc
- Abhik Chowdhury
- Paula Leonova

### Agenda:

- Overview of current and planned features for QF
- Add any topic you would like to chat about below

(what did you learn by using QF? What do you wish QF could do? Or any of other questions/topics!)

- Abhik & QF signup process & questions
  - Confusion regarding public data sharing on "open humans" vs. sharing the data within the QF project
  - Maybe there can be status badges of things to do in an activity (to see things that could still be done)
  - Fitbit connection & Fitbit intraday do these have to be repeated?
    - Bastian: these do update routinely, like daily, this should be communicated more clearly
    - Not sure if the fitbit intraday is connected properly, don't see a data tab
      - Yes, this probably indicates it's not working
      - How to fix not clear that configuration is done on the project website, not on the main OH site
- QF rose/thorn/(bud?) what do you like, what do you dislike/wish were better?
  - Mad: like seeing my symptom data visualized with wearable data, frustrated that I don't have much idea what others are doing... would like to see more about what others are experiencing, maybe highlight specific interesting experiences.
  - Gary: like feeling that my wearable data is stored somewhere where something good might be done with it. thorn/wish would like to see this data against \*other\* types of "background" data
  - Dave: managing supplements & diet for my health (homocysteine, zinc) and interested in this
    project because it motivates me to do more (e.g. concern abt overactive immune system,
    cytokine storm).

- Abhik: despite the issues earlier I shared, this is much easier than it was to do it myself to get/see data connected. Would like to see feedback/updates on what data is being used for, maybe newsletters
- Morgan: would be good to see what other people are doing with it
- Paula: haven't tried QF, curious about the general application where a group of people are contributing & opening up the data within a project space. Reducing hiccups/issues for joining helps get more people to participate if they don't have much intrinsic motivation.
- Bastian: rose/like: it's interesting to scroll my data and see things that look like "signals" but I didn't report any symptoms which makes me wonder whether past "events" were just by chance. thorn/missing: no way to input "weird causes for physiological signals" there was a night where I'd had alcohol and that affected sleep/RHR. Annotating in retrospect.
  - "Notes" already exist, but not adding reflections on data after it's been collected and visible
  - Gary: this touches on an important affordance missing right now annotation of your own data, it's a recording/representation of your own learning process. It suggests it's another layer on top of the data collection or visualization layer.
- Paula: there are places that coordinate visualization resources for projects that would like to have data analyzed, and they'd probably be interested in working with you
  - Bastian: maybe it helps to have more specific
    - Mad: I'd like to see interesting individual stories
    - Bastian: how many people have gotten sick while doing QF? What's that look like?
  - Abhik: ability to create more custom symptoms
    - Paula: adding to that, would like to explore others that are doing that type of tag (e.g. migraines) explore data from others that are tracking the same thing
- Paula's notes on programs that offer data science opportunities whose participants might be good contributors to QS: https://insightfellows.com/data-scienceData Incubator, Metis are a few other bootcamps that come to mind. Colleges also have started to reach out to companies for projects, such as Northeastern.
- Closing round what value do you see in QF, whether or not you're doing it yourself?
  - Paula I like to see how this relates to general experiences in understanding learning processes
  - Bastian it's improved my "adherence" to collecting this data prompt with easy email links, and visualizing the data I collected
    - Paula added note: I don't think all these benefits, easy reminders, visualization, reminders those are all not obvious if you haven't done it yet.
  - Gary promise of using my data in relation to symptoms, even though haven't realized its personal value yet
  - Dave I like how it makes people more conscious of their health, generally more interested in predicting/improving health. Maybe it could be a survey question how conscious are you of your health
  - Abhik for the project itself, as someone going into grad school, I see a lot of them being asked to invest a lot to build something to ask a specific question – QF demonstrates how a more flexible framework (OH) can be used to build projects more easily.
     connecting/aggregating across supersets of data is interesting.
  - Vitali valuable to see if wearable data can be used to predict getting sick
- Keating Memorial Show & Tells on Thursday at 10am Pacific / 7pm CEST. Register at:
   <a href="https://docs.google.com/forms/d/e/1FAIpQLSfL-ApfINY3R669fqEn9W2mmw1vnfCTa2pWod0jFjfXIS-jSw/viewform">https://docs.google.com/forms/d/e/1FAIpQLSfL-ApfINY3R669fqEn9W2mmw1vnfCTa2pWod0jFjfXIS-jSw/viewform</a>

# July 16 (Self-research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: <a href="https://zoom.us/j/196519106">https://zoom.us/j/196519106</a>

Recurring calendar event: <a href="https://tinyurl.com/ya6pu3nv">https://tinyurl.com/ya6pu3nv</a>

#### Attendees:

- Mad Ball
- Gary Wolf
- Richard Sprague
- Eric Jain
- Steven Jonas
- Abhik Chowhury
- David Blackwell <a href="https://my.pgp-hms.org/profile/huFE0257">https://my.pgp-hms.org/profile/huFE0257</a> Atrial Fibrillation Eliquis B12, D3, Zinc

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### Non-attendees

James Littlejohn (might be around for the second half but will be around 23rd.)

## July 14 (Community Call)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/i/196519106

Recurring calendar event: <a href="https://tinyurl.com/yamkozvj">https://tinyurl.com/yamkozvj</a>

#### Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- Abhik Chowdhury Abhik.ch6@gmail.com
- David Blackwell <a href="https://my.pgp-hms.org/profile/huFE0257">https://my.pgp-hms.org/profile/huFE0257</a> Atrial Fibrillation Eliquis B12, D3, Zinc
- Gary Wolf
- Morgan Hough

### **Topics**

- Keating Memorial Self Research Show&Tell on Thursday July 23 (10am PDT / 7pm CEST)
  - o RSVP here: https://forms.gle/UHpwR4PXUD3npW4q7
  - Must RSVP to get Zoom link!
- Next week's meeting: focus on Quantified Flu & invite QF contributors/members
- Bastian (mostly) sharing "in development" and "ideas" with Open Humans activities & cetera
  - Morgan couple things hoping to do
    - "my spectrogram" using OH to upload data from Muse headset, few minutes of resting data, get a couple derived measures
    - also trying to use this hardware and openBCI hardware to collect research grade data
  - o Autistica / Turing citizen science
    - started around a year ago, grant to do a citsci to allow people with autism or caretakers, report things that went "really well" or "really badly" (e.g. "today I had to take the tube in london and it was really stressful")
    - using OH to collect data anonymously, and can anonymously share with researchers (can decide "publicly available" or "with researchers" or both). trying to implement some review.
    - iterating development, reviewed by community. learned that "just share experience" doesn't work well → too open-ended, especially for folks with autism! it's overwhelming to try to answer "what happened during my day", they need more specific Qs
    - target end of year
  - Covid-Open survey developed at the CRI (where Bastian is based)
    - asking about physical health, mental wellbeing, medication reporting
    - a lot of Qs are one-off, and goal is to have these Qs be designed by the community
    - same set-up as autistica: sign up anonymously via OH, send emails/reminders via OH. Copies of all the survey responses to be returned to participants via OH. Then, hoping to have publicly available aggregate data, so people can compare their personal responses to the aggregate.
    - variety of people helping build this around the world. some academic affiliated, but basically a big mix of people contributing.
  - o iGEM competition usually people do synth bio but... because of pandemic, CRI students decided to do microbiome
    - lockdown vs. post lockdown, have people interested in seeing their microbiomes

- use OH to register, and write their IDs when sending samples back
- return raw data from sequencing back to people, hope to make fun analysis around it
- o JOGL rather than "using" Open Humans, improving it
  - grant to connect JOGL systems to OH, so "open needs" posted in JOGL are visible on the activity pages in Open Humans
  - a way to get more community features into Open Humans, more interactivity to the Open Humans activity pages
- CRI Tremor Watch (based on Arduino)
  - not really Open Humans project, but more in open hardware direction maker lab at CRI and has been looking at espruino now. Interested in how these can be used for people with disabilities. Got something working that measures the frequency and intensity of tremor, they've worked out the pipeline for collecting and analyzing this data
  - Gary do you have a link? Bastian can ask if there are slides to share, as usual documentation lags
  - Made own variant of arduino board, 3D printing casing etc. Don't need to solder, at least, use an existing board. Wirelessly get data off it, live picture of current signal.

## July 09 (Self-Research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/i/196519106

Recurring calendar event: <a href="https://tinyurl.com/ya6pu3nv">https://tinyurl.com/ya6pu3nv</a>

#### Attendees:

- Mad Ball
- .Bastian Greshake Tzovaras
- .James Littlejohn
- .Miguel Rochefort
- Richard Sprague
- .Paula Leonova
- .Abhik Chowdhury
- .Gary Wolf
- .Steven Jonas
- Eric Jain
- .Christopher Wansing
- .Aditya

### **Topics**

- Background on the Keating Memorial: https://www.openhumans.org/self-research/
- Tentative plan: Keating Show & Tells on the 23rd (instead of our weekly call)
- Add your topic here!
- Hayfever Keating Research
   https://docs.google.com/presentation/d/1GYGS3S\_c3INe\_r36IX5fNZAsPUcgmIUOB5T977Wtixg/edit?usp=sharing
- Updates:
  - o Gary brief updated
  - Steven quick, feedback on spreadsheet
  - o Bastian visualization I'm playing with
  - o Paula small update
  - o Aditya brief, what I've been collecting, hope to do
  - o James a bit of analysis I'd like to share
  - o Eric self tracking body temp, playing with air quality monitors
- Gary I'd moved from tremor tracking to arrhythmia, but haven't abandoned the tremor tracking
  - been using one-button to track arrhythmia, and tried to use it to track bites of food
  - every day since last week I tried to do it. and every day I failed! in daily life there's invariably a meal which has too much distraction. couldn't manage to get a 24 hours.
  - o ... so, just going to treat the "meal" as an event. much simpler
- Steven
  - o shared spreadsheet of daily goals and bonus goals, and whether they succeeded
  - Richard have you tried pomodoro method? Steven it doesn't work very well for me, one that does work well is switching between two tasks
    - smaller increments work better but tracking that adds too much

- Eric: why did you involve your brother?
  - Steven: it was working better as a QS project, e.g. I was doing blood pressure readings, and talking w/ brother wasn't scheduled so that became impossible. I thought it might help him (he actually tried the pomodoro method and got it to work for him), the daily interaction worked really well for us, and became an opportunity to chat about things.
  - Steven: also I think I learned a lot by watching someone else. We also had a "don't give each other advice" rule.
- James Hayfever self-tracking analysis
  - https://docs.google.com/presentation/d/1GYGS3S\_c3lNe\_r36lX5fNZAsPUcgmIUOB5T977Wtixg/edit?usp=sharing
  - Plan had been to experiment with fasting and see if it had an effect on hayfever. but pandemic put a stop to this – didn't seem wise to potentially impact immune system
  - tracking symptoms in spreadsheet. record severity 1 to 5, subjective and generally relative to the day before
  - o checked which symptoms dominated. unsurprising to me, dominated by sneezing, itchy eyes. the eyes are partly due to no longer using eyedrops.
  - o plotted symptoms, they seem cyclic. might be because going outside triggers severe symptoms, and then I avoid it → gets better. might try to use wearable data to correlate and say which "outside" days were active
  - o also measuring air quality, and one outside. my sense is rain or windy is worse symptoms, curious if data supports that.
  - Gary: what's your most urgent question?
    - James: in the past, I quit medication at the start of august, because it puts me to sleep. I want to avoid the medication because it has this effect
    - last year I quit drugs during peak, but didn't do that this year because caregiving for family and didn't want to be going in with apparent "flu symptoms"
  - Eric: when are you tracking? once a day, or multiple times?
    - James: mainly at lunchtime, sometimes an update in the evening (especially if I went outside)
- Paula took online course and tracked when studying for it
  - o used atimelogger, sometimes used "comment" feature
  - o and used rescuetime, curious what resources I was using in addition to the coursework
  - o am writing a blogpost about it
  - questions I'm wondering about how my scheduled changed, when I actually ended up studying (mostly weekends?)
  - Eric: Did you have any subjective feeling of "this was a productive session"?
    - Paula: after about two hours felt like I reached flow state
  - Steven: it's interesting to see how spaced repetition and meta awareness of effective studying is really interesting reflections to see
    - Gary: moments that feel good / satisfying vs. bad are interesting to reflect on
    - Paula: reaching a milestone was rewarding. deadline also helped! this course was going to expire after 3 months. sense of pressure made me feel like I was "always studying" (but that wasn't true!)
- Aditya stuff I'm collecting, wanting to do with it
  - have fitbit, typical activity tracking
  - o have been logging thoughts in an app that collects other data weather/GPS, mood
    - have almost 3000 thought logs, past 5 years, really curious about what I might be able to see in these things, also in combo with google search history, other data
    - don't have a question right now, but feel like I can do more as I learn ML and analysis
  - o Richard: what was the app? Adi: it's called <u>Journey</u>, can export all of it

- Bastian: low hanging fruit for analysis is to look at periodicity not even looking at the content, what times do you log
- Richard: another app I've tried is <u>Reporter</u>, which prompts you randomly. Adi: unfortunately I'm using Android, Reporter is only iOS
- Steven: this is a presentation on analyzing text messages: <a href="https://vimeo.com/53727798">https://vimeo.com/53727798</a>
- Steven: also curious what prompted you to start doing this at 15
  - Adi: I like to collect things, logging anything significant to my life. sometimes I wonder if it's narcissism, but I think it's that it's valuable to me I don't expect others to care about and it helps me think about stuff, decide what I want to do
- Gary: thinking about real time sense of the archive, "The Social Memex" by Mark Carranza: quantifiedself.com/blog/the-social-memex/
- Bastian sharing trying to visualize time series of elevation changes in travel over time
  - Richard: did you look into <u>aganimate</u> Bastian: I really want the 3D as it's more appealing, rather than 2D plots of the elevation changes
  - Mad: I fantasize about wanting something interactive, where you can slide along timepoints Bastian: unfortunately it's rendering an interactive 3D you can rotate, each time, and it's just not possible to render each of those on the fly (takes too long)
  - James: maybe the three.js community has ways?
     <a href="https://blog.mapbox.com/bringing-3d-terrain-to-the-browser-with-three-js-410068138357">https://blog.mapbox.com/bringing-3d-terrain-to-the-browser-with-three-js-410068138357</a>
    - or maybe Babylon
  - Eric: I like how the garmin interactive dashboard works, and as you highlight a timepoint on one chart, you can see it highlighted in other charts on the same page
- Keating memorial Show&Tell in two weeks RSVP <a href="https://forms.gle/UHpwR4PXUD3npW4q7">https://forms.gle/UHpwR4PXUD3npW4q7</a>
  - o folks that would like to present should try to do practice/draft talks in our meeting next week!
  - Draft invitation below:

Please join us for self-research "show&tell" talks in honor of Steven Keating, hosted by Open Humans and Quantified Self. If you have a self-research topic to present, be sure to note it in the RSVP.

RSVP HERE (For security and good meeting management, you must RSVP to be admitted to the Zoom!)

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### July 07 (Community Call)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/i/196519106

Recurring calendar event: <a href="https://tinyurl.com/yamkozvj">https://tinyurl.com/yamkozvj</a>

#### Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- Aditya (Adi)
- Paula Leonova
- David Blackwell <a href="https://my.pgp-hms.org/profile/huFE0257">https://my.pgp-hms.org/profile/huFE0257</a> Atrial Fibrillation Eliquis B12, D3, Zinc

DG1

### **Topics**

- What's Open Humans?
- The Keating memorial: <a href="https://www.openhumans.org/self-research/">https://www.openhumans.org/self-research/</a>
  - o About steven: <a href="http://news.mit.edu/2019/celebrating-curious-mind-steven-keating-0722">http://news.mit.edu/2019/celebrating-curious-mind-steven-keating-0722</a>
- Live demo of the notebook bastian presented at QS: https://exploratory.openhumans.org/notebook/163/
- Interactive maps: <a href="https://exploratory.openhumans.org/notebook/126/">https://exploratory.openhumans.org/notebook/126/</a>
- What to do re Keating memorial
  - o Having a collection of QS Show & Tells of KM participants would be very nice
- How to handle public sharing when there's a small number of participants
- Join our slack: slackin.openhumans.org

## July 02 (Self-research chat)

Didn't take place due to the Quantified Self Europe meetup

## June 30 (Community Call)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/j/196519106

Recurring calendar event: <a href="https://tinyurl.com/yamkozvi">https://tinyurl.com/yamkozvi</a>

#### Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- Sam Chen
- Gary Wolf
- Katarzyna Wac
- Paula Leonova
- Kwok Ng
- David Blackwell <a href="https://my.pgp-hms.org/profile/huFE0257">https://my.pgp-hms.org/profile/huFE0257</a> Atrial Fibrillation Eliquis B12, D3, Zinc
- Add your name!

### **Topics**

- Updates to Quantified Flu visualization of symptom tracking + activity tracker data
- Let's talk about the Puck.js open source "button" sensor
- Invitation to the JOGL meeting today
  - Tue, June 30, 2020
  - 11:00 AM 12:00 PM PDT
  - https://www.eventbrite.com/e/iogl-live-1-with-quantified-flu-tickets-111136586522
- Invitation to the QS Show&Tell on Thursday
  - https://forms.gle/R7rWGv2vc94sCcRi6
  - o Topic: QS Show&Tell Online
  - Time: July 2, 2020 07:00 PM CEST
  - o Presentations will be in English. Chat can be in any language!

### **Add Your Topic:**

# June 25 (Self Research Chat)

- Go around:
  - Mad no updates, been busy
  - o Paula updated notebook & Bastian
  - o Gary update about food and arrhythmia

- o Steven brief update about nature of goals, and idea for next project
- o Richard no big updates, been playing around with RHR notebook and have feedback
- o Bastian not much, can share a bit about using bangle for motion tracking
- Paula notebook for visualizing rescuetime
  - Original: <a href="https://exploratory.openhumans.org/notebook/161/">https://exploratory.openhumans.org/notebook/161/</a>
  - Widget: <a href="https://exploratory.openhumans.org/notebook/162/">https://exploratory.openhumans.org/notebook/162/</a>
  - o Richard: diff between "open" and "edit and run"?
    - Bastian: open = loading voila interface, edit & run gives the regular jupyter interface
    - General observation might be helpful to set aside some time to discuss the overall system & what we wish it would look like; Gary: maybe setting aside 2-3 hours to step back and think about what we'd like a system for reusable analysis notebooks to look like
  - Note that legend is currently "off" and is a true/false toggle, for potential privacy issues
    - toggle also for the x-axis, which someone might want to not have displayed
    - can modify date range, or run as a window up to now (e.g. last 7 days)
    - can specify a subset of categories to be the only ones displayed
  - Q from Gary: are the tags custom tags, or native to rescuetime?
    - They're native to rescuetime. Within rescuetime you can also create custom tags, and customize what things are considered "productivity" or not.
  - Steven: wanted to share talk from Madison Lukaczyk. Paula I saw that one:)



- Show&Tell How Work Distractions Affect My Focus
- Gary: might be nice to reach out to RescueTime, show how their data can be used in reusable notebooks
- Gary tried logging everything I was eating but it was too much work & wasn't seeing clear signals.
  - So... trying using another 1-button tracker and pressing the button every time I take a bite.
     Going to try this for a couple days, worked well at breakfast. So... output will be "density of eating"
  - o My prediction is that the arrhythmia isn't really triggered by food at all, despite my intuition
  - Richard: why do you think food might be a trigger? what about getting up, walking around?
    - Gary: the food thing is based on my intuition... feels like stuff happens after I eat lunch. but that's really rough, and mealtimes aren't stable.
    - Richard: are you wearing a device that can tell when you're standing, activity? Gary: yes... but I do stand while I work
  - Mad: it sounds like you're more concerned about what you eat, but when you eat
    - Gary: I think the type of food might matter and maybe I'd explore if it seems like there
      is any sense that it really is occurring with timing related to meals
- Steven: minor observation on goal setting feels like a "cheat" to set a goal that you had to do anyway, deciding whether you need to set a different (additional) one

- Been very interested in a <u>psychomotor vigilance task</u>. usually used to test sleep deprivation. stare at screen, something pops up, tap as soon as you see it. using app called <u>Vigilance</u> <u>Buddy</u>.
- o Curious about a sense of circadian rhythm & attention. Also curious about Ultradian rhythms
- Richard: there's an app airline pilots use before getting into cockpit Seth Roberts had his
  own app (you can <u>download it here</u>), and I've used it ... Seth found that testing throughout the
  day had too much variability; ended up picking one time each day and just do it then
  - Richard: one interesting thing he found was that alcohol didn't seem to matter (!)
- o Steven: there was also a tool Genomera had that I used for used, but then disappeared
  - I think I tried getting that app that Seth used, but had trouble getting it
- Paula: reflection on goal setting, often I hear the opposite, to the point of writing things down that has already been done & giving oneself credit for it, vs. feeling overwhelmed by large undone goals
  - Steven: yeah, it's interesting to explore the different strategies people use. Setting up a game you know you'll win (but why do that?) ... also situations where I think "I need to get X done first" and then asking myself "then why didn't I make that my goal for today?"
- Richard: updated notebook a bit to get weekly averages, and latest data seems to be closer to the same time last year.
- Gary: I went along to try the RescueTime notebook had some questions about it...
  - o Do you download the app and RescueTime integrates across devices?
  - Bastian: there is no RescueTime for iOS devices... the app doesn't track usage, at least, you can
    use to visualize
  - Paula: I've heard of ActivityWatch as an open source alternative... curious because I'm no longer able to get granularity of Chrome usage, maybe ActivityWatch works
- Bastian: added a link for PuckJS can use to track location Paula had wondered about this earlier
  - http://forum.espruino.com/conversations/329950/
- General request would be great to have a list of potential one-button uses!

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## June 23 (Community Call)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/j/196519106

Recurring calendar event: <a href="https://tinyurl.com/yamkozvi">https://tinyurl.com/yamkozvi</a>

#### Attendees:

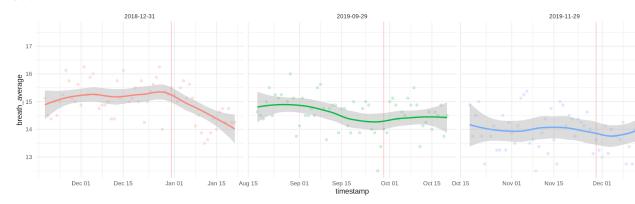
- Mad Ball
- Bastian Greshake Tzovaras
- Richard Sprague
- Gary Wolf
- Morgan Hough
- Paula Leonova
- David Blackwell https://my.pgp-hms.org/profile/huFE0257 Atrial Fibrillation Eliquis B12, D3, Zinc
- Add your name

#### Notes:

- Mad: discuss press stuff around wearable companies that are claiming detection of covid-19 how do we feel about it, opinions & reflections.
  - Gary: wondering if this will produce a group of people interested in the "signal" being discussed, possibly dubious of claims and interested in exploring it themselves possibly interested in engaging in Quantified Flu
  - Links to the announcements:
    - Whoop: <a href="https://www.whoop.com/thelocker/predict-covid-19-risk/">https://www.whoop.com/thelocker/predict-covid-19-risk/</a>
      - using respiratory rate at night
      - seems to try to distinguish symptomatic people, between covid-19 vs. non-covid-19
      - detecting pre-symptomatic but much lower rate
    - Oura:

https://wvutoday.wvu.edu/stories/2020/04/08/wvu-rockefeller-neuroscience-institute-and-oura-health-unveil-study-to-predict-the-outbreak-of-covid-19-in-healthcare-professionals

- one of maybe half dozen oura studies, using aggregated oura-supplied research database
- Oura is mostly using RHR
- this stuff ends up turning into claims like: https://twitter.com/TheNBACentral/status/1273667511788109829
- Gary: Does Respiratory Rate decrease or increase with COVID-19
  - Bastian: made quick graphs based on non-COVID events:
  - See



- See heart rate and temperature in https://exploratory.openhumans.org/notebook/83/
- Bastian: can talk a bit about playing with BangleJS to make one button

## June 18 (Self-research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: <a href="https://zoom.us/j/196519106">https://zoom.us/j/196519106</a>

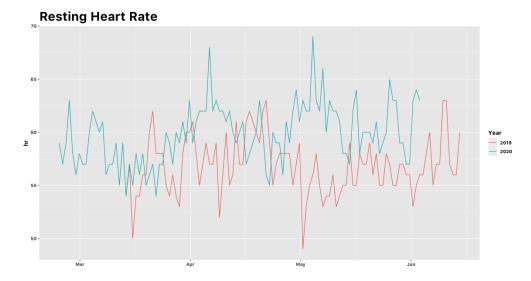
Recurring calendar event: <a href="https://tinyurl.com/ya6pu3nv">https://tinyurl.com/ya6pu3nv</a>

#### Attendees:

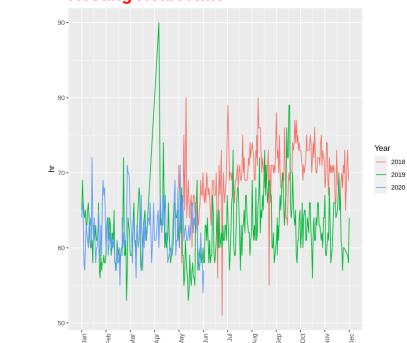
- Mad Ball
- Bastian Greshake Tzovaras
- James Littlejohn
- Richard Sprague
- Gary Wolf
- Katarzyna Wac
- Steven Jonas
- Paula Leonova
- Add your name

#### Notes:

- Write down your updates!
  - Mad: nothing to report, trying to track mood vs weekly T but mood tracking is crap lately, doing well if I get one per day
  - Kat: tracking RHR hoping to correlate with monthly cycle, hoping to present next week
  - Bastian: no updates on self-research but can share some stuff I did with bangle
  - James: no updates but from talking to others, local surge in a lot more hayfever so stuff seems worse for everyone right now
  - Richard: hoping to discuss RHR mystery (seems to be significantly higher than a year ago, no explanation)
  - Gary: Quick update on continuous ecg quest.
  - Paula: no updates, will share link to OS presentation I gave Tuesday
  - Steven: no updates on my project but want to talk about scope & thinking about new projects
  - Miguel: nothing this week
- Steven quick Q to Paula & Mad, did you learn anything via putting together the presentations for the show&tell
  - Mad I looked harder about the estimated "start date" for my illness and found from chat records it was probably even later than I'd thought, which was surprising
  - Paula got feedback that the charts were overwhelming, learned to build out how to look at the data (start with single day, then zoom out). reflecting on "action items" I had a new one, going outside in any way reduces device/screen time. really appreciated the guestions.
- Richard:
  - https://exploratory.openhumans.org/notebook/124/
    - just the rendered notebook: <a href="https://exploratory.openhumans.org/render-notebook/124/">https://exploratory.openhumans.org/render-notebook/124/</a>
  - RHR seems to be going up over the long term this is concerning



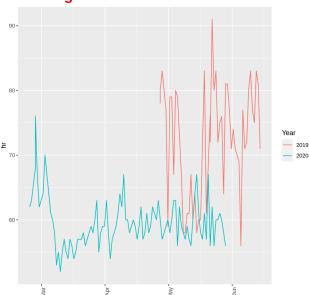
**Resting Heart Rate** 



- Mad:

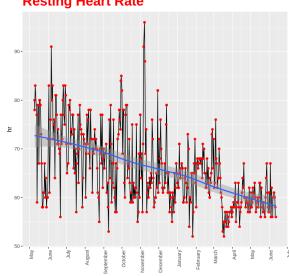
- (higher values in 2018 due to being pregnant until Dec 26)





Bastian:

**Resting Heart Rate** 



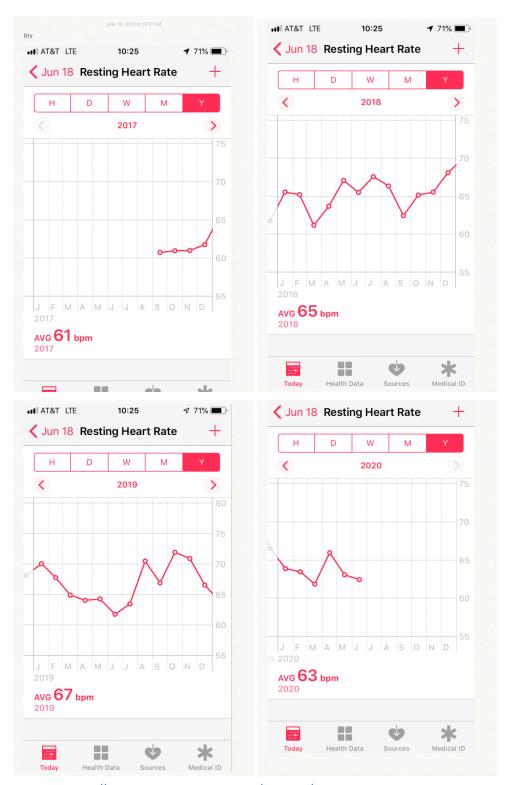
- At first thought this was seasonal, but comparing between years looks very different
  - Kate: have you changed device?
    - Richard: Apple Watch the whole time

Steven: 2017 (Sept-Dec) 61

2018: 65

2019: 67

2020: 63 (started wearing to bed in March)



- https://www.openhumans.org/activity/oh-data-port-for-apple-health/
- Gary: finding continuous ecg monitor
  - following on Q from Mad: how do you know the qualitative experiences are correctly lining up with actual data/events?
  - so far been unable to find a device that has exportable data :( everything is "export PDF, share PDF with doctor"

- Richard: are you looking at something that tells you # of missed heart beats per day?
  - Gary: or per period of time, or look for when time-between beats is excessively long (maybe HRV type data)
    - requires access to a good record, detailed data about heartbeats... and processing the data
  - Richard: what device do you use for heartrate
    - Gary: charge 3... but does that have this data?
    - Bastian: you can get intraday data with per second resolution: https://fitbit-intradav.openhumans.org/
    - Bastian: it doesn't create a CSV but I'd be happy to make a notebook that converts the JSON to CSV for you
    - you can also use GDPR to get really detailed data, beyond what we get
      - Kat: I'd be interested in more info about this, and trying it... we've been trying to use the intraday API with same issues
      - Bastian: it can take months, a long time, not for realtime or short term
      - How to get \_all\_ of your fitbit data using GDPR:
         <a href="https://mathias-schindler.de/2018/05/20/bsdg-fitbit-privacy-access/">https://mathias-schindler.de/2018/05/20/bsdg-fitbit-privacy-access/</a> (German)

#### - Steven

- Reflecting on the current self research project & Qs about scope with these weekly meetings
- I do feel like I should finish the one project before I start sharing another
- Mad: I think sharing new projects makes sense! It's nice to have continuity of one project over time, but really natural to start new projects and have them grow & maybe overtake what used to be the main one

## June 16 (Community Call)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/i/196519106

Recurring calendar event: <a href="https://tinyurl.com/yamkozvi">https://tinyurl.com/yamkozvi</a>

#### Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- Gary Wolf
- Katarzyna Wac
- Morgan Hough
- David Blackwell <a href="https://my.pgp-hms.org/profile/huFE0257">https://my.pgp-hms.org/profile/huFE0257</a> Atrial Fibrillation Eliquis B12, D3, Zinc

#### Notes

- Updates QF
- Jupyter Notebooks & Dashboards
- Quantified Self meetups! There's one tonight (PDT)

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• Add your topics here!

ANNOUNCEMENT: QS Show&Tell Online Meetup: June 16, 6 pm Pacific Time (US)

### Details

Please join us for an online conversation on self-tracking where we share ideas, tools and experiments with the global Quantified Self community.

This meeting will take place online in Zoom:

https://zoom.us/j/7740567825

(Feel free to share this invitation with others.)

We'll have our regular show&tell format with a focus on some interesting projects relating to self-tracking for COVID-19 and using self-collected data for advance warning of sickness onset. If you have a project in this area, please let us know when you RSVP. Check out quantifiedflu.org to see how some people in the QS community are tracking their symptoms.

Here's our agenda (All times are PDT, UTC-7):

Intro and Announcements - 6:00 pm

Presentations - 6:15 to 7:15

- -Bob Troia: What I use to monitor for infection.
- -Mad Price Ball: Looking back on a sickness event. Can I see something in the data before my symptoms?
- -Paula Leonova: Charting life changes since shelter-in-place began.
- -Shara Raqs: Infectious illness or extreme stress? Fertility tracking data and understanding ambiguous symptoms.
- -Plus more! Let us know if you have a project to share when you RSVP.

Wrap-up & Group Conversation - 7:15 to 7:30

## June 11 (Self-research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/j/196519106

Recurring calendar event: https://tinyurl.com/ya6pu3nv

#### Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- James Littlejohn
- Richard Sprague [^1]
- Gary Wolf
- Steven Jonas
- Paula Leonova

#### Notes:

- [^1] Richard will be on another call but will watch this space in real time and respond when possible, so please take good notes!
- People with updates
  - o Mad: no updates
  - o Gary: Has some slides
  - o Bastian: only more general things
  - o Steven: Just a verbal update
  - o Paula: looked at notebooks
  - o James:
- Where to find notebooks: <a href="https://exploratory.openhumans.org/">https://exploratory.openhumans.org/</a>
  - o (notebooks are then run via notebooks.openhumans.org)
  - o Blog post on <a href="https://blog.iupyter.org/and-voil%C3%A0-f6a2c08a4a93">https://blog.iupyter.org/and-voil%C3%A0-f6a2c08a4a93</a>
  - How to make widgets
    - https://github.com/jupyter-widgets/jpywidgets
    - https://github.com/jupyter-widgets/ipyleaflet
  - o GPS data: overland.openhumans.org
  - Mad: can widgets trigger heavy computation that hasn't happened yet, so the page "loads" without having to do heavy computation first (i.e. triggered by the widget interaction)?
    - Bastian: in principle I think they can be used that way, haven't tried yet
    - note that limitation may be the type of data, note that JSON data you have to load the whole thing before you can use it
  - Gary: is the memory something you decide? Bastian: it's the memory available in the virtual machine that users each get
  - Gary: a working group of people trying to create & use notebooks, could be a good step towards building out support & make them usable and reusable
  - o Bastian: it's hard to think outside your own experience to actually enable re-use, because you have assumptions (e.g. hard-coding only looking at June 2019, instead of providing a widget)
  - James: how hard is it to take a visualization widget from one notebook and use it in another
    - Bastian: for the interactive map I copied from an existing notebook and just edited the last couple lines to put my own data in. if it's coming in as a fairly standard dataframe or CSV it's easy to plug a new one in

- Bastian: we have a lot of JSON data because we stored it "the way we got it" but a
  drastic improvement would be a library for standardized CSV-ization would make this
  all more friendly
- Steven: switched to using google spreadsheets to record during meetings with brother. Previously using phone database, but tracking adherence dropped off. Thought maybe it was too difficult to switch devices to record on phone while talking on skype with laptop, and using speech to text. Typing in the spreadsheet resulted in much better data collection.
- Gary: sharing slides
  - https://docs.google.com/presentation/d/ISDc53-HHjwhwZcVU0wfOoPkBWtSomEBB8XpX27Lj
     3YQ/edit?usp=sharing
  - o kardia & 1-button for tracking arrhythmia
  - extended tracking demonstrates how variable the phenomenon can be, helps stepping away
     from local fluctuations (tempting to say "oh I'm cured! oh it's gotten terrible!"
  - noting recent events, potential stressors. started using eventloggers for ~2 weeks to track stuff like caffeine, alcohol, but stopped – burdensome to do and wasn't seeing anything obvious
  - o 1-button data seems to indicate that it's getting worse later in the day... don't know why, potential trackers (eating?)
  - o case crossover design idea:
    - record potential triggers in previous time window, rather than continuously track
    - note: rigorousness requires pre-defining which triggers will be recorded, and what time window to record
    - how to record preventative factors?
      - Mad: are the preventative factors not just a time window thing, so not recorded
        in the same way? reflection this relies on your ability to remember stuff in the
        time window, and it feels like some types of triggers are easier to recall with
        confidence in a longer time window, but others hard to recall confidently more
        than a short window
    - James noting circadian rhythm effects might be related?
  - o Bastian it seems like there's some periodicity over the weeks / months
  - Mad: there's also possibility you aren't noticing events maybe you're simply more aware of events later in the day.
    - Gary: that's what I'll need the continuous device to investigate; working on getting this. as for missing events, my sense is that this happens, but not for the severe events
    - Gary: I wonder if that would imply that I should only record the very bad events
  - Steven: one thing I wonder about is that when you want to track triggers, whether the
     1-button method will work for you because you need to do more each time, creates a barrier to engaging in tracking
    - Reporter is known for random sampling, and you can use it to fill out a set of other information (e.g. the triggers) but that's extra work to do
    - Gary: that's a good point, often I'm not taking the button out of my pocket at all. I wonder... if there's a way to do it, e.g., look at the end of the day, then think about triggers in the preceding 12 hour period.
- James wondering what usefulness machine learning has for quantified self approaches
  - o e.g. want machine learning to predict my activity tomorrow
  - Mad tangential but maybe of interest, AI in democracy vs authoritarianism, one point is emphasizing reducing need for "big data" for effective AI/ML (as authoritarian entities benefit more from "big data" approaches)
    - https://cset.georgetown.edu/research/shaping-the-terrain-of-ai-competition/
      - which is relevant for self-research / QS stuff, because you want to be able to train and use something just using your own data

- Steven: reminded about someone that got a ML prediction for his mood, and it was pretty good at predicting a negative trajectory – but less good at predicting positive changes – and it was interesting how the role of this thing was how it started a dialog: "oh you predict it's going down, because less exercise? maybe I should move more"
  - Mad: relies on explainable Al! :)

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# June 9 (Community call)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/j/196519106

Recurring calendar event: <a href="https://tinyurl.com/yamkozvi">https://tinyurl.com/yamkozvi</a>

#### Attendees:

- Mad Ball
- Adrian Gropper
- Sam Chen
- Morgan Hough
- Dave Blackwell
- Gary Wolf
- Liubov Tupikina
- Sebastien Treguer
- Ben Carr

#### Notes:

- JupyterHub updated & Voila is implemented. Example notebooks...
  - "Run notebook" launches the voila version (code hidden); "Edit & run" has the traditional version (code visible & editable)
  - o <a href="https://exploratory.openhumans.org/notebook/124/">https://exploratory.openhumans.org/notebook/124/</a>
  - o Gives an interactive map dashboard: <a href="https://exploratory.openhumans.org/notebook/125/">https://exploratory.openhumans.org/notebook/125/</a>
- Morgan: wondering about minimal examples of how to upload data to Open Humans
  - o activity for self-upload of files, with data types: <a href="https://upload.openhumans.org/">https://upload.openhumans.org/</a>
    - define data types here: <a href="https://www.openhumans.org/data-management/datatypes/">https://www.openhumans.org/data-management/datatypes/</a>
    - ^^ the notes field can be used to explain how to get the data, what structure it's expected to have
  - o or, APIs to upload activity-associated data:
    - https://www.openhumans.org/direct-sharing/oauth2-data-upload/
    - there's also python (open-humans-api) & django libraries (django-open-humans) that make it easy to build apps that manage getting and adding data to accounts

## June 4 (Self-research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/j/196519106

Recurring calendar event: <a href="https://tinyurl.com/ya6pu3nv">https://tinyurl.com/ya6pu3nv</a>

#### Attendees:

- .Mad Ball
- .Bastian Greshake Tzovaras
- Gary Wolf
- .David Blackwell <a href="https://my.pgp-hms.org/profile/huFE0257">https://my.pgp-hms.org/profile/huFE0257</a> Atrial Fibrillation Eliquis B12, D3, Zinc Gluconate.
- .Steven Jonas
- James Littlejohn
- .Paula Leonova
- .Katarzyna Wac
- .Richard Sprague
- Miguel
- Frank
- Abhik Chowdhury

#### Notes

- Chat about Bangle.JS: https://banglejs.com/
  - Join the #banglejs channel on the Open Humans Slack to chat about it
- Updates:
  - Steven: some updates on Mental Contrasting
  - Paula: have an update on dashboard for collecting timelogging data, fitbit, rescuetime
  - Bastian: no updates about my project, but can share graphs comparing bangle to apple watch heartrate
  - Kate: some updates on period tracking & wearable
  - Dave: some stuff to share re atrial fibrillation tracking, blood pressure, diet
  - Richard: playing with OH data upload to use Apple Watch heartrate, combo the data can share graphs
  - Abhic: some updates on hardware I'm building, hoping to do visual life logging
- Steven Mental contrasting
  - slides (ongoing updates as doing the project)
  - <a href="https://docs.google.com/presentation/d/1p7HEcSH3FKnLr7v0\_UKn-zU4e-B9hoWBzs7rND5jw">https://docs.google.com/presentation/d/1p7HEcSH3FKnLr7v0\_UKn-zU4e-B9hoWBzs7rND5jw</a> <a href="EA/edit?usp=sharing">EA/edit?usp=sharing</a>
  - Added: slides about the Ninox app used to collect data (create databases on your phone, very flexible)
  - Added impressions: warm feeling about the project even though tracking is kind of failing (!), has faltered the past few weeks. Maybe from the social aspect?
  - Planning to try to analyze data collected (e.g. blood pressure vs. goal success)
  - Steven: One thing that I'm struggling with these presentations is how much background info to give. I don't want new people to feel lost, but I don't want to bore people by giving the same spiel everytime. I'm trying to split the difference by sharing the presentation, but don't know how effective that is.

- I'm also thinking that it would be better to not have the presentation in full screen and clicking through all of the slides. It can be disorienting to have the presenter quickly click through things. It would be better to have the slide drawer open and only click on the slides that I will be discussing.
- Paula collecting time tracking data plotting automatically collected data (fitbit, rescuetime)
  - plotted sleep, device/screen time, activity & movement
  - plots with many more things split out (e.g. refined by activity recorded by rescuetime) hard for others to read, but can remember/recreate a day
  - pre/post pandemic graphs
  - Steven for device time, does TV count? Paula yes, if it's on my computer. Otherwise (and other people's computers) that data isn't captured. Bastian using rescuetime on phone? Paula can't track exact URL on my phone, will need to use google history data.
  - Miguel have been doing a very similar project, using google calendar for visualization. would love to try using your visualization code. regarding tracking, on Android "ActivityWatch" (<a href="https://activitywatch.net/">https://activitywatch.net/</a>) is an open source alternative to RescueTime
  - Blog post: <a href="https://pleonova.github.io/shelter-in-place/">https://pleonova.github.io/shelter-in-place/</a>
  - Repo: <a href="https://github.com/pleonova/data-diary">https://github.com/pleonova/data-diary</a>
- Abhik trying to do visual and audio 24/7 logging. interested in humanizing insights on what's occurring during my life.
- Kate tracking resting heartrate on fitbit, should visualize & show. Last cycle, the oura ring score was 55 3x days in a row, and increased body temp, and felt weird was worried would like to hear if other's have had such low scores. In the end I seem fine, but was worried.
- Dave
  - Kardia report from last month, recording atrial fibrillation, classifies reports.
  - https://drive.google.com/file/d/1c2qXvjR7-Arz7hQMGVzDctlJ090Na\_b7/view?usp=sharing
  - Purpose of the device is to see when in atrial fibrillation or tachycardia, because otherwise often don't notice. Trying to find a pattern or cause so far not finding any medication seems to have helped
  - 23andMe data, livewello report rs1021737, high homocysteine? may cause other issues, and how this interacts with dietary factors & supplements
  - Gary suggest trying to putting this together as a show & tell talk
- Richard graphing heartrate from apple watch exported via the open humans app
  - noted heartrate up, coincided with calories
  - Paula: which app do you use ot track diet? Richard: cronometer, best I've found, I used to use myfitnesspal but cronometer is better for people doing self-tracking
- Bastian exploring bangleJS data
  - within webbrowser; can connect to device, and download the data stored on the device
  - heartrate jumps all over & claims high confidence (even high confidence recordings are very noisy)
  - comparing 5m average interval averages btw apple watch and bangle correlation of zero. It looks like the raw data from the bangle is very rough.
  - maybe more accurate if you aren't moving. even if very snug, though, movement causes the heartrate to be very inaccurate.

### From chat (feel free to add anything of note!):

- Abhik: This seemed like a cool course, I was thinking about getting it! https://www.medcram.com/courses/ekg-ecg-interpretation-explained-clearly
- Bastian: Not wanting to take up time for this, but I did much coarser-grained analyses in the same vein on lockdowns with rescuetime and oura too, with the notebooks being on open humans: https://exploratory.openhumans.org/notebook/122/ and https://exploratory.openhumans.org/notebook/121/ (scroll down for the graphs)

- Dave: I find an ionizing air filter to work well for my allergies.

## June 2 (Community Call)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/i/196519106

Recurring calendar event: <a href="https://tinyurl.com/yamkozvi">https://tinyurl.com/yamkozvi</a>

#### Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- Gary Wolf
- Dave Blackwell
- Christopher Wansing
- Katarzyna Wac
- Jonathan Brier
- Morgan Hough
- Rogier Koning
- Paula Leonova
- Ben Carr
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### Topics:

- Virtual Quantified Self meetup
  - o OS Sign up Link
  - o If you have a self-tracking project you'd like to present, let us know
  - Doesn't need to have a major discovery or conclusion, really interesting for people to see what you're doing – and maybe learn how to do stuff
  - Ask everyone to show some observation graph, chart, or table
  - Fixed link Signup for QS Show&Tell June 16 <a href="https://forms.gle/RZuUUevLCqpAtqL37">https://forms.gle/RZuUUevLCqpAtqL37</a>

O

- Status: JupyterHub / Voila
  - Tim Head is available & time to update & maybe get voila dashboards installed at end of this week
- EEG
  - Morgan sharing <a href="https://neurotechx.com/">https://neurotechx.com/</a> and a project for making it easier for people to collect and use EEG data: <a href="https://github.com/NeuroTechX/eeg-notebooks">https://github.com/NeuroTechX/eeg-notebooks</a>
  - o needing more people to collecting data to better understand how to use it, goal is to make it empowering, talking to <u>Open Source Brain-Computer Interfaces (openbci)</u>
  - o variety of equipment out there, e.g. muse headsets
  - o has thought about using openmined, federated learning wo sharing specific data
  - Ben more info about the turnkey system. Morgan shares neurotechx system. reflecting on hair issues (using forehead + behind ear to avoid this issue). openbci gets a few more

- channels. having electrodes in the back needed for visual cortex if any interested in visual activity
- Mad wondering about interest in Open Humans. Morgan interested in data sharing models and experiences other projects have had. Interested in "if you share, you get access to federated learning" (e.g. open mined – not access to each other's individual data)
- Paula wondering about intrinsic bias on those who choose to share vs. general population.
   data sets are often biased though, e.g. child mind institute biased for children referred due to behavioral issues
- Bastian interested in resting EEG or specific tasks, both? Morgan interested in extended longitudinal data, usually that's resting but that could be repeated tasks too. Bastian - when thinking about this in the past, had trouble seeing the "use case" – what is the individual value for someone to collect their own data.
- Gary noting the issue is that an interesting research question soliciting data from others
  that would be interesting if enough people did it, it's tough to get people involved in
  contributing. Important to start by providing value to individuals that isn't requiring the mass
  goal. Bastian note that there's already a community of thousands collecting it and would be
  interested in seeing the research questions answered. Morgan hoping to answer questions
  people bring to neurotechx
- Christopher is it just EEG or any other data? demographics? activity? Morgan open-ended what people could work on
- Updates on Quantified Flu
- For Ben: What's new on the BOSC sticker exchange? :D
  - o I don't think that's REALLY relevant here....
    - But I think I am going to do it, much to the chagrin of my wife
- From Dave, shared link: "Vitamin D Sunshine Optimal Health: Putting it all Together" on YouTube <a href="https://youtu.be/B9SNfrE7Pls">https://youtu.be/B9SNfrE7Pls</a> This is a great video on the importance of nutrition and especially vitamin D3 during this Covid 19 crisis.

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## May 28 (Self-research Chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/i/196519106

Recurring calendar event: <a href="https://tinyurl.com/ya6pu3nv">https://tinyurl.com/ya6pu3nv</a>

#### Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- James Littlejohn will be 5mins late
- Steven Jonas
- Miquel Rochefort
- Danny Lammerhirt
- Gary Wolf
- James Littlejohn
- Abhik Chowdhury
- Please Add Your Name

### Topics:

- Steven Jonas mental contrasting project updates
  - o checked in with brother "is this working for you/us?" → structure seems to help trying productivity methods that wouldn't otherwise have been tried
  - o thinking about trying a bonus daily goal feels "easy" vs "hard" goal (maybe personal vs work)
- Gary minor update on arrhythmia project (could share if not many others)
  - o last week talked about using kardia (home ekg) and 1-button, got a dx from doc of PVCs
  - using eventloggers to track common triggers (caffeine, alcohol). arrhythmias went away recently, challenging so far (eg more caffeine) doesn't seem to have made them come back (?)
  - o thers to track/correlate exercise, sleep, heart rate from the fitbit device I already have, planning to see if they explain the lower symptoms
- James allergies project & wondering how to quantify antihistamine effects
  - o allergies recently better, medications seem to be working (wanted to avoid them)
  - wondering about interrelations of mood & allergies, worry a bit about what effects of antihistamines have (short and long term)
- Mad ideas for what wishlists people have for analyses, anticipating notebooks will be upgraded soon to add voila
  - Gary generally, timeline visualization. zoomable data. also, giving visualize normal range (std dev, don't call it that) ...visualization when a variation is really unusual. A lot of people not used to data don't realize a "blip" is just a blip due to natural variation.
  - James shared toolbars, which things to visualize together, maybe these could be incorporated into notebooks <a href="https://youtu.be/SYwUeVBXi4A">https://youtu.be/SYwUeVBXi4A</a>
  - Bastian shared a vis of rare/unusual data (from genetics);
     <a href="https://en.wikipedia.org/wiki/Manhattan\_plot">https://en.wikipedia.org/wiki/Manhattan\_plot</a>
  - Danny what ways are there to look at data needed/used in QS that aren't generally available? Gary – just a moving/rolling average seems simple but is often really helpful.
  - Steven example, shared link to <a href="https://github.com/arielf/weight-loss">https://github.com/arielf/weight-loss</a> an example of an idea of how to analyze the data, I imagined I could re-use for things other than weight, but it was

just a bit too hard for me to do myself. Making it really easy to ask a question makes it easier to explore, e.g. "slicers" in spreadsheet to really quickly re-do the visualization with filters on the data.

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## May 26 (Community Call)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/i/196519106

Recurring calendar event: <a href="https://tinyurl.com/yamkozvi">https://tinyurl.com/yamkozvi</a>

#### Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- Christopher Wansing
- Kate Wac
- Gary Wolf
- Richard Sprague
- Melvin Fribourg
- Ilona Bussod
- Danny Lämmerhirt
- Justin Adams
- Dave Blackwell
- Abhik Chowdhury
- Please Add Your Name

#### Topics:

- Latest QF updates:
  - Data visualizations
    - Ilona & Melvin present some updates:
      <a href="https://docs.google.com/presentation/d/ly04OZlopYFJmVC9-dLA7lr9MCM\_YZBDYcfD">https://docs.google.com/presentation/d/ly04OZlopYFJmVC9-dLA7lr9MCM\_YZBDYcfD</a>
      <a href="https://docs.google.com/presentation/d/ly04OZlopYFJmVC9-dLA7lr9MCM\_YZBDYcfD">https://docs.google.com/presentation/d/ly04OZlopYFJmVC9-dLA7lr9MCM\_YZBDYcfD</a>
      <a href="https://docs.google.com/presentation/d/ly04OZlopYFJmVC9-dLA7lr9MCM\_YZBDYcfD">https://docs.google.com/presentation/d/ly04OZlopYFJmVC9-dLA7lr9MCM\_YZBDYcfD</a>
      <a href="https://docs.google.com/presentation/d/ly04OZlopYFJmVC9-dLA7lr9MCM\_YZBDYcfD">https://docs.google.com/presentation/d/ly04OZlopYFJmVC9-dLA7lr9MCM\_YZBDYcfD</a>
      OucsvNo/edit?usp=sharing
    - Daily diary of Ilona & Melvin where the code is written:
       <a href="https://docs.google.com/document/d/1QbbmOtdFyU0\_MpAqSOlvsAncCXtT0DK5m2w">https://docs.google.com/document/d/1QbbmOtdFyU0\_MpAqSOlvsAncCXtT0DK5m2w</a>
       R1AVZM7c/edit?usp=sharing
    - A quick preview: Symptom-report heatmaps are now there: https://quantifiedflu.org/report/list/member/79502270
    - Discussion confounding factors for RHR? Bastian: How much you sleep (not enough → never got low during the night)
      - Christopher: more activity → doesn't get low
      - Richard: also, how much you eat (for me doubling how much I ate caused it to go up by 20bpm (!))
      - Kat: for me alcohol also, can cause it to go up 2-5
      - Bastian for Richard, how hard is that?! (doubling calorie intake) Richard: you can buy high calorie drinks; I've always been on the thin side & it's because I eat less, I just have to eat a lot more
    - Abhik: hardware question based on graphs comparing fitbit vs oura, slide 9 you were able to see RHR change on Oura device but not Fitbit – is that right? is that because RHR is more distall? i.e. a hardware thing, or software and algorithms...
      - Melvin: there is a huge similarity between the two, so... I don't think it's the software causing the variation

- Mad: also note a lot of this data is from one person, so it's hard to know how idiosyncratic or universal it is Bastian: the fitbit might slide around, not as tight, while the Oura may be more consistently worn
- Abhik: any literature regarding efficacy of different locations of the body? Kate: the gold standard is the chest, don't know if there's been study of the finger/ring with Oura itself. Bastian: I recall someone wearing two Oura rings & seeing discrepancies between those even, so fingers may not be that consistent too.
- Mad: may speak to consistency of how you use your own device
  - Bastian: with the fitbit, this might be harder to do, different spacing on the band on different days is possible
- Gary: you can get a picture of reliability of your device by watching own data
- Latest changes
  - Redesign front page:
    - Switched symptom reports & retrospective events
- Working on
  - Editing/Deleting symptom reports
  - Adding past symptom reports that were missed
- Hoping to do outreach please feel free to share with others, would be great to have more folks contributing
- o Dave: have been you collecting info about supplements?
  - Bastian: short answer is no, but we've also thought about adding one-off questionnaires that people could do as well
  - Richard: Apple Health keeps track of nutrition stuff like that, does the OH uploader get that?
    - Bastian: not yet, but it could be added
- Short experiment: Video Motion Magnification Making pulse visible (Christopher)

Add your topics!

## May 21 (Self-Research Chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/i/196519106

Recurring calendar event: <a href="https://tinyurl.com/ya6pu3nv">https://tinyurl.com/ya6pu3nv</a>

#### Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- Christopher Wansing
- Gary Wolf
- Katarzyna (Kate) Wac
- Miguel Rochefort
- James Littlejohn
- Add your name

### **Topics**

- Gary: Triggers of Arrhythmias
  - using kardia mobile doctor went ahead with using this data for diagnosis (great!)
  - doctor noted that 1-button recordings might not be accurate because many people don't notice missed beats at all – get diagnosed due to a \*coincidental\* ekg (!) – so curious about whether this is true for myself & interested in getting continuous data
- Christopher Wansing:
  - Circadian Rhythm in Core Body Temperature
  - Heart Rate from Head Movement (Blood ejection into the head, causes slight movements)
  - Heart Rate from Camera (Color Variations on Skin)
  - Kate: what device? Christopher: Using cosinuss device
    - lasts ~6 hours, rechargeable
    - PPG, temp, IR for spO2, accelerometer
    - no onboard memory needs phone in range to record data (planning to add this to future, hopefully firmware update); raw data via a subscription to cloud storage/management of €30/month (expensive)
  - o Kate: how comfortable?
    - Christopher: not as comfortable as airpods, but not terrible. version with round insert a bit more comfortable. adjustable fit.
  - o Mad: you mentioned this has just 6 hours, the 12-day device is a different device?
    - Christopher: it's a different device and will only have temperature. same company.
      - the 1 device is available, the 2 is more expensive and out of stock
      - few devices that get medical-quality data; another is the dream headband I've used to get ppg data
  - o Reflection on raw data access vs. PDF export only with medical data (as is true for kardia!)
- Miguel: Passive time-tracking
  - Time-tracking manually with google calendar for over a year. at first a minimum of 15 minute intervals after a while it gets tedious to remember to do
  - o tried adding all the sensors I have to add contextual data, automatically collected
    - sleep via watch, steps (activity), motion sensor in room (wyze cam), touch sensor on bathroom door, detecting which room I'm in via bluetooth sensor

- track calls, usage of a specific device (e.g. a thinkpad), chromecast / other media
- using knowme to aggregate
- want to improve this so can zoom in and see more detail; this display is maybe just a quarter of the data
- Gary: the limitation of zooming is a common issue in QS data, it's interesting to hear how you're tackling it
  - Miguel: working on a zoomable display with JS right now
- Christopher: difficult to have different data types visualized at once, how to organize them so you can see and distinguish them
  - Gary: Here is an example of integrating data with very different temporal resolution, from an older QS talk:
     <a href="https://quantifiedself.com/blog/randy-sargent-using-spectrograms-visualize-heart-rate-variability/">https://quantifiedself.com/blog/randy-sargent-using-spectrograms-visualize-heart-rate-variability/</a>
  - Miguel: maybe according to sense, e.g. "everything you hear" in one column,
     "rooms/location" should all be their own
- o Bastian: how do you do the bluetooth location
  - Xiaomi Miband broadcasting + MELIFE 2 Pack picking up on signals
  - Christopher: bluetooth 5.1 should make it possible to do triangulation & get better measure of location. Miguel: I knew wifi can use time of signal to infer distance, didn't know bluetooth was developing similar. Christopher: can do it with multi receivers duing angle & timing of signals; before now proprietary tech but now freely available with bluetooth 5.1 and anticipate more companies doing this stuff more cheaply possibly with centimeter accuracy
  - Christopher: the bluetooth beacon rather than relying on the phone is more reliable, phones have services shut down in background
- Bastian: are you alone, is the bathroom sensing others?
  - Miguel: yeah, I have to curate that data, there's three people here
- Christopher: There are smarthome sensors detecting when someone walks through door (and direction) (can use it to count number of people in a room, trigger lights) - <u>Homematic</u> <u>Walkby Sensor with direction</u>
- o Gary: you mentioned using nomie, how do you use it?
  - Miguel: I used to track lots of things, e.g. every sip of water. To make it easier I've been using NFC tags, tap my phone to tag the event
  - Gary: NFC tags on all these things? Miguel: different tags linked to different knowme information category. sometimes one tag used for a set of things all together (e.g. all the supplements I always take together)
  - https://nomie.app/
- Add your topic!

# May 19 (Community Call)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/j/196519106

Recurring calendar event: https://tinyurl.com/yamkozvi

#### Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- Please Add Your Name
- James Littlejohn
- Abhik Chowdhury
- Frank Kao (WareAbouts)
- Gary Wolf
- Ben Carr

### Topics:

- Latest QF updates:
  - o Apple Watch is finally supported
  - Feature wishes
    - Redesign front page:
      - "Report button" now is too hidden
      - Switch symptom reports & retrospective events
    - Editing/Deleting symptom reports
    - Adding past symptom reports that were missed
- Bastian: Related to last week's Bangle.js discussion: Any experiences with Puck.js? Looks like it might make a nice one-button-tracker! <a href="http://www.espruino.com/Puck.js">http://www.espruino.com/Puck.js</a>
- Open Humans pipelines

## May 12 (Community Call)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/j/196519106

Recurring calendar event: https://tinyurl.com/yamkozvj

#### Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- James Littlejohn
- Noah Robischon
- Katarzyna Wac
- Ben Carr
- Eric J Daza
- Abhik Chowdhury
- Gary Wolf
- Danny Lämmerhirt
- Add yourself here!

### Topics:

- Chatting about Quantified Flu, Open Humans, and related projects
  - How many contributors are there now?
    - About 130 joined, and ~50 publicly sharing their symptom tracking logs
    - Not much growth recently as we've held off outreach while trying to get additional data sources -- google fit now here, apple watch in progress
  - Tell us please where you need help besides visualization? Any new wearables to be connected?
  - Updates:
    - Google Fit is there
      - Ben: Note on Google Health, doesn't seem to be added to the stand alone google health export
    - Working on a data visualization:
       <a href="https://observablehq.com/@basilemorane/heatmap-of-simptoma-reporting">https://observablehq.com/@basilemorane/heatmap-of-simptoma-reporting</a>
    - The Apple Health export saga continues
- via James: Open smartwatch! <a href="https://banglejs.com/">https://banglejs.com/</a>
  - James the way companies like fitbit, etc operate, is a pattern of controlling the data, not empowering the individual. A lot of the ones that are more open source/hardware go bankrupt (Pebble was great, and now it's gone).
  - o Bluetooth, using Gadgetbridge for notifications to the phone
  - As always, challenges with making it easier for people, but this seems to have a great potential with the libraries & design – would be good to have community feeding into it, contributing
  - Bastian: maybe similar to the card10, opensource "badges" (that were really smartwachts) and a small app store for it:
    - https://card10.badge.events.ccc.de/media/assembly\_flyer.pdf overview over the badge10
    - "App store": <a href="https://badge.team/badge/card10">https://badge.team/badge/card10</a>

- Abhik: maybe a good opportunity for open source algorithm development for feature extraction
  - discussion of academic work in interpreting raw data to steps... now academic focus is more on intervention, personal utility
  - Abhik: wonder if one could put data on kaggle, invite people to try to develop algorithms Mad: it's something Open Humans could help with Bastian: openSNP did something like this, via crowdAl running a competition on genetic data prediction
- https://banglejs.com/apps/
- o And electronics IDE <a href="https://www.espruino.com/ide/emulator.html">https://www.espruino.com/ide/emulator.html</a>

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Add your topics here!

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# May 7 (Self research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: <a href="https://zoom.us/j/196519106">https://zoom.us/j/196519106</a>

Recurring calendar event: <a href="https://tinyurl.com/ya6pu3nv">https://tinyurl.com/ya6pu3nv</a>

#### Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- Steven Kaye
- Steven Jonas
- Frank Kao (WareAbouts)
- Katarzyna (Kate) Wac

### Agenda:

- Steven Kaye sharing work with self-research on glycemic response
  - From Kate, maybe of interest: See the analysis of glycemic response for <a href="https://journals.plos.org/plosbiology/article?id=10.1371/journal.pbio.2005143">https://journals.plos.org/plosbiology/article?id=10.1371/journal.pbio.2005143</a>
    - used dexcom
- Bastian quick analysis, observation of lockdown impact on sleep and activity <a href="https://twitter.com/gedankenstuecke/status/1257969330807025664">https://twitter.com/gedankenstuecke/status/1257969330807025664</a>
- Chatting about ideas on interventions on life during lockdown
  - o morning routines, getting outside do a walk to get coffee, gardening
  - Steven Jonas: idea for activity –
     https://thalliatree.wordpress.com/2018/01/13/evil-russian-pushup-program/

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# May 5 (Community call)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/i/196519106

Recurring calendar event: <a href="https://tinyurl.com/yamkozvi">https://tinyurl.com/yamkozvi</a>

#### Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- David Blackwell <a href="https://my.pgp-hms.org/profile/huFE0257">https://my.pgp-hms.org/profile/huFE0257</a> Atrial Fibrillation Eliquis B12, D3, Zinc Gluconate.
- Abhik Chowdhury
- Katarzyna Wac (Kate)
- R Sterling Snead

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## Agenda:

- Chatting about Quantified Flu, Open Humans, and related projects
  - How many contributors are there now?
  - Tell us please where you need help besides visualization? Any new wearables to be connected?
- Add your agenda items
- Anyone interested in seeing my Livewello, Nutrahacker, Promethease, or other DNA report that I have on my DNA? David Blackwell. Also I am interested in how you examine your DNA results.
- Kate: Need pointer to a smart toothbrush enabling to collect some detailed stats
  - o Oral B has their own app
- •
- •

## April 30 (Self research chat)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/j/196519106

Recurring calendar event: <a href="https://tinyurl.com/ya6pu3nv">https://tinyurl.com/ya6pu3nv</a>

#### Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- Please feel free to add your name below if planning to attend
- Steven Jonas
- (Katarzyna Wac)
- Danny Lämmerhirt
- Gary Wolf
- Robin Groenke
- Miguel Rochefort
- James Littlejohn

### Agenda:

- Chatting about our self research projects and ideas
  - o Bastian finally prepared his Blood Glucose data!
- Please feel free to suggest agenda items (tag with your name please!)
- James did an update on his hay fever tracking. Summary on forum https://forums.openhumans.org/t/fasting-effect-on-hayfever/312/3
- Steven's slides

# April 28

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/i/196519106

#### Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- Please feel free to add your name below if planning to attend
- Katarzyna Wac
- Gary Wolf
- Steven Jonas
- Rogier Koning
- Karolina Alexiou

## Agenda:

- Updates on Quantified Flu
  - o API endpoints
  - o Basile joins Bastian in Paris to work on data visualizations
- Add your topics of interest

### Notes

• random notes – Life Slice: https://www.youtube.com/watch?v=rpcnuvD4Xw8&list=UU0T4qlfOGlQbWOOj-adGiew&index=24

# April 23 2020 (Self research updates)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/i/196519106

### Meeting focus:

Chat about self research projects you're working on, share updates and advice.

See also: <a href="https://www.openhumans.org/self-research/">https://www.openhumans.org/self-research/</a>

Note: Based on discussion during our April 14 meeting, we decided to hold additional meetings with more specific focuses.

#### Attendees:

- Mad Ball
- Olivier Mirat
- Steven Kaye
- Zhassulan Zhaniyazov
- Please eel free to add your name below if planning to attend
- Steven Jonas
- Gary Wolf
- Bastian Greshake Tzovaras
- Katarzyna Wac

### Agenda:

- Chatting about our self research projects and ideas
- Please feel free to suggest agenda items (tag with your name please!)
- Gary: I can share a couple of visualizations from my self-tracking data made with this tool: <a href="https://gotsafan1.github.io/time-series/index.html">https://gotsafan1.github.io/time-series/index.html</a>
- •
- •

#### Notes:

- Intros
  - Mad: my own self research has just ground to a halt, and hoping this chat motivates me to restart, and
  - o Olivier: working on self-tracking for chronic pain
    - http://www.monstermizer.com/ → recently changed to myAlguide
  - o Bastian: my self-tracking research with glucose, got data but haven't gotten to analyzing it...
  - Kat: been tracking my resting heart rate... less exercise and more stress, it's higher than I'd like now. also can see my monthly RHR and noticing menstrual cycle influence
  - Mickey Vallee researching communities, how people are self-tracking, and how people are making meaning in this situation and maybe sometimes seek 1-on-1 conversations
  - Gary I want to follow up with Kate re cycle tracking stuff. And... I think my self-tracking data reveals why I'm having trouble with my self-tracking project
- Gary: using 1-button to track episodes of cardiac arrhythmia

- Steven: is the visualization tool here something the Totte Labs provides for 1-button analysis?
- o Gary: yeah, it's a simple visualization tool they've shared that has number of presses organized by buckets in time over the day
- Steven: are you keeping track of missing data?
  - Gary: The days with "missing data" really had no events, I know that because I did it. But yeah, there's a lot of struggle with "missing data" and in this case I happen to know it was really no events.
- Olivier: what's the motivation for the self-tracking?
  - Gary: it gives me a psychological benefit to understand the phenomenon, to have a concrete record that it's occurring. plus I have these personal theories I can look at now, e.g. "more in the afternoon"... and maybe a dose threshold for caffeine ... those are both potential experiments I haven't actually done yet.
  - maybe avoid taking a second cup of coffee on certain days and see if that changes it.
     or have a very light lunch and see if that affects it.
- Steven: tracking as a way of changing your relationship with the phenomenon, stepping away a bit as an observer of yourself. do you feel it interelates to meditation practice?
  - Gary: hadn't thought about that, interesting to think about
- Steven: reflecting on the advice of Alan Neuringer from previous discussion (comparing qualitative self-report from event to event, calibrating yourself to a previous classification), another valuable link is this from Seth Roberts about the Willat Effect:
  - https://sethroberts.net/2011/07/08/the-willat-effect-side-by-side-comparisons-create-connoiss eurs/
    - → "Side-by-Side Comparisons Create Connoisseurs"
  - Gary: it reminds me of how food conneisseurs work, and evolving their own taste by the act of trying to classify and characterize food
- Mad: it makes me think about how what anyone does in self-tracking becomes more specialized not
  just to adapt to what they needed at first, but customized to their own expertise that is, it wouldn't
  have been an ideal tool for themselves as a newcomer nor for anyone else
  - and it makes me wonder about the re-usability of protocol that one person has developed, how much others can re-use it – do we become connesseurs of the same thing, or is it deeply custom and introspective
  - o Gary: my thought is that the importance becomes around configurability and re-usability around things that are more generic, like the 1-button tracker
  - Steven: I find that things that worked for me don't work later, so even solving it for yourself doesn't keep working later because people change
- Steven Jonas: catching up with intro my own project was to do "mental contrasting" with positive/negative thinking and trying to follow a protocol in the book with daily goals.
  - o blood pressure rise → more likely to complete a task?
  - also, my brother's doing this together with me. so we chat every morning about what we
    want to do. the mental obstacles feel a lot like what might come out during therapy. been
    using a rule to not give advice.
  - o Kat: what kind of goals?
    - Steven Jonas: I think the technique might work well for longer term goals like month, daily goals have been harder to pose. process-type goals like "spend X minutes on this today" rather than results oriented. But basically like TODO list stuff.
    - Kat: when you set up a goal do you estimate how hard / feasible it is?
    - Steven Jonas: that comes back to the self-calibration process... and how important is it to make an easy goal. with my brother we're learning from each other, sometimes in different directions though (e.g. one being easy on oneself, the other pushing to get tons done)
      - I find "negative thinking" can help discourage overreaching

- o Olivier: are you tracking something?
  - Jonas: I'm doing blood pressure before and after. but to do them properly I have to sit for 5m without moving or speaking... and when I started I was doing e-ink app to record process. switched to a voice to text app and saved to database, and this was easier. but maybe that's messing with blood pressure reading. and now I'm doing it with my brother and speaking a lot, maybe effecting blood pressure measurement. and sometimes forgetting that.
  - Gary: what are you trying to learn from the blood pressure
    - Jonas: curious if I can reproduce what they claimed in their research
    - Gary: so the goal is higher blood pressure means you're going to achieve the thing
  - Gary: so... I've done a lot of blood pressure on myself and driven myself crazy with the various confounding things, where it is on arm, etc ... and recalling Seth's hassles with this, trying 3 measurements with 3 devices... feels like a black hole with trying to get precise measurements. how are you dealing with this crazy variability in trying to do blood pressure measurement?
    - Steven Jonas: I'm kind of doing it because I don't believe the research
      - also trying a prediction based on how I'm feeling, how motivated I'm feeling. and I'm somewhat able to predict... I don't think I'm going to discover much from it, I'm not concerned about whether it results in a "finding", more of a side narrative.
    - Gary: I guess my approach would be to do three measurements in a row post hang-up.
- Steven Kaye: update on my own stuff stuff at work has made me have a lot less time for data analysis... I've maintained the experiments themselves, testing macronutrients and getting data, seems to be solid dose response
  - tested a handful of "keto" ingredients, most seem to have claimed lack of effect on blood sugar, but one did not (! had a large effect seems that I can't trust nutrition labels)
  - o for my own sanity, doing analyses less frequently

# April 21 2020 (COVID-19 related projects & features)

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Zoom videochat link: https://zoom.us/j/196519106

### Meeting focus:

Quantified Flu and other activities/projects related to Open Humans that are related to the COVID-19 crisis.

Note: Based on the popularity of the April 14, decided to hold additional meetings right away.

#### Attendees:

- Mad Ball
- Carolina Brum
- Ulrich Genick
- Zeno Davatz, ywesee GmbH
- Daniel Boschung
- Gary Wolf
- James Turner
- Marja Pirttivaara
- Iain Henderson
- David Blackwell <a href="https://my.pgp-hms.org/profile/huFE0257">https://my.pgp-hms.org/profile/huFE0257</a> Atrial Fibrillation Eliquis
- Joe Bedell <a href="https://mv.pap-hms.org/profile/hu19C09F">https://mv.pap-hms.org/profile/hu19C09F</a>
- Katarzyna Wac
- Ines Potočnjak
- mickeyvallee
- Ben Carr
- Robert Sloan
- James Littlejohn
- Bastian Greshake Tzovaras

#### Agenda:

- TBD
- From Zeno Davatz: Draft for study announcement
- Updates on QF
  - Work on Apple Export
  - Submitted a small grant to JOGL
  - How to expose the symptom reports?
- External projects:
  - o James Turner & makethemasks.com
  - CoughApp
  - CrisisLogger in development
  - CRI-led survey project
- Please feel free to suggest agenda items (tag with your name please!)

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- Searching for natural human genetic variations that protect against infection by the
- COVID-19-Virus (SARS-CoV-2).
- Like all other viruses, SARS-CoV-2 relies on our body's own proteins (enzymes, receptors,
- transporters etc.) to enter into and replicate inside our cells. These proteins are encoded in
- our genome. As humans show extensive genetic variation among one another, it is likely,
- that some of these genetic variations will also affect some of the proteins, that the virus
- relies upon on to infect us. Individuals carrying certain genetic variations may therefore be
- much less susceptible to infection by the SARS-Cov-2 virus.
- A well-known case of such virus-protective genetic effects is the variant of the CCR5 gene,
- which protects individuals carrying two copies of this variation against infection by common
- strains of HIV. Another case are variations in the FUT2 gene, which give near complete
- protection against the most common strains of the Norwalk Virus a highly infective Virus
- causing severe gastrointestinal symptoms. As the case of the FUT2 gene shows, such virus-
- protective genetic variations can be very common (20% of Caucasians are genetically
- protected against this virus.)
- We want to use a citizen science-based genome-wide association study (GWAS) to search
- for common virus-protective genetic variations in the general population. For this project
- we are looking for individuals who possess and are willing to publicly share their personal
- genome data (e.g. from 23andMe, Ancestry.com or a similar direct-to-consumer genetics
- testing service.) and who
- a) were strongly exposed to the virus (e.g. multiple people in the same household were
- affected) but who did not become infected themselves.
- b) Who were exposed to the virus and became infected.
- Rationale (for Bastian, Eimear etc.)
- The study gambles on the possibility, that a very common (e.g. >20%) variant of very large,
- near-mendelian effect size exists. If this is the case, a relatively modest (by GWAS standards)
- cohort size of a few hundred individuals may be sufficient to detect such a genetic variation
- in a GWAS study even when phenotyping (as is expected in the current setting) will have
- substantial flaws.
- Certainly, larger and better planned GWAS studies on this topic will be conducted in the
- future
- But, given the importance and immediate utility of potential findings (e.g. individuals
- carrying virus-protective variants would be able to help keep up essential services at
- moderate risk of infection) as well as the relatively modest effort required to conduct the
- study, we feel that a rapid study that may deliver near immediate results will be an
- important complement to the more thoroughly planned larger studies that will certainly
- follow.
- Regarding ethical concerns, it would be ideal, if the study could rely primarily on individuals
- who have already shared their genomic data publicly (e.g. OpenSNP) or who are willing to
- do so. In such a scenario the study would be a secondary use of existing publicly available
- and anonymized data.

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# April 14 2020

10:00 PDT / 13:00 EDT / 18:00 BST / 19:00 CEST

Google calendar event link: <a href="https://tinyurl.com/sagwegg">https://tinyurl.com/sagwegg</a>

Zoom videochat link: https://zoom.us/i/196519106

#### Agenda:

- Opening round how are people managing during the coronavirus crisis?
- Do people want more frequent community calls (e.g. every 2 weeks?)
  - People are happy with every two or even every week
    - Will try another next week and see what happens
- What's new with...
  - Ouantified Flu
    - wishlist & known bugs is anyone out there wanting to contribute and what do they need
  - Open Humans
    - adding apple watch data
    - adding overland for android (GPS self-tracking)
    - trying to add apple login for Open Humans
- Add your own topic!

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### Attending:

- Bastian Greshake Tzovaras (Open Humans & CRI Paris)
- Please feel free to add your name below if planning to attend!
- James Littlejohn
- Ines Potočnjak (Croatia)
- Katarzyna Wac
- Gary Wolf
- (Dave) David Blackwell <a href="https://my.pgp-hms.org/profile/huFE0257">https://my.pgp-hms.org/profile/huFE0257</a> Atrial Fibrillation Eliquis
- Hernán Morales Durand
- Steven Kave
- Eric J. Daza
- Jan Taco te Gussinklo
- Adrian Gropper
- Chang Lu
- lain Henderson
- Steven Jonas
- Robin Groenke
- Dawnie
- Chang Lu
- Robert Sloan
- Konstantin

• Benjamin Carr

## March 26 2020

10:00 PDT / 13:00 EDT / 17:00 GMT / 18:00 CET

Google calendar event link: <a href="https://tinyurl.com/tzrldlt">https://tinyurl.com/tzrldlt</a>

Zoom videochat link: https://zoom.us/i/196519106

#### Agenda:

- Quantified Flu & other projects related to COVID-19
  - https://quantifiedflu.org/

#### Attending:

- Please feel free to add your name below if planning to attend!
- Mad Ball
- Bastian Greshake Tzovaras
- (Sarah Williams)
- Michel Chabot
- caroline
- Shreyasi
- Stephen Albers
- Ammar Husami
- Christopher Wansing
- Steven Kaye
- Otto Kekäläinen / fevermap.net
- Caroline Corum
- Gary Wolf
- Yong Huang
- Karolina

#### Meeting notes:

- Open Humans API documentation: <a href="https://www.openhumans.org/direct-sharing/oauth2-features/">https://www.openhumans.org/direct-sharing/oauth2-features/</a>
- Mad referenced <u>Open mHealth</u> as an example that involved a lot of thinking about data standards for sharing but was not widely adopted.
- Fevermap preliminary data format / API design document:
   <a href="https://gitlab.com/fevermap/fevermap/-/issues/13">https://gitlab.com/fevermap/fevermap/-/issues/13</a>
  - We were wondering if we can choose semantics/API/data formats that facilitate sharing the data inside the open data community
- Ice breaker question: Who's currently on lockdown? :D
- Social distancing in Finland at the bus stop.



#### Feature ideas

- Compare your own retrospective signal visualization to the overall cohort of all contributors
- Gary: More qualitative data on reports would be useful (e.g. is higher RHR due to going out for drinks or falling sick)
  - explanations for "why" data might be different (if it is)
  - (Actually displaying recorded reports (would encourage more note-taking?)
  - this might be due to medication, known behavior (e.g. drinking alcohol), chronic conditions
- Allow symptom reporting on the site directly + retrospective reports
- Notes field for retrospective reports:
  - What did I have?
- Caroline: How about the problem of chronic conditions changing how physiology responds?
  - Bastian: I've seen people asking for chronic conditions at <a href="https://coronaisrael.org/en/index.html">https://coronaisrael.org/en/index.html</a>
  - Mad: this raises the question of whether we should be wanting to collect any demographic data
  - Gary: trying to disentangle whether causality is due to a chronic condition (or other demographic characteristic) is probably difficult to do from a pure numbers method (getting "enough people in mass" to see average answers emerge) rather think about focusing on enabling processes for individuals to connect causality themselves and report those
- James: I wish I had an immunity index prevention rather than explanation

## March 10 2020

10:00 PDT / 13:00 EDT / 17:00 GMT / 18:00 CET

Google calendar event link: <a href="https://tinyurl.com/tyjc8pg">https://tinyurl.com/tyjc8pg</a>

Zoom videochat link: https://zoom.us/j/196519106

## NOTE: Timezone changes mean this is an hour earlier than typical for Europe!

## Attending:

- Mad Ball
- Bastian Greshake Tzovaras
- Katarzyna Wac
- Liubov Tupikina (not speaking?)
- James Littlejohn
- Li-Yuan Hung
- Rochelle Shen
- Steven Kaye
- Greg Austic
- Gary Wolf
- Eric Jay Daza
- Dave Blackwell huFE0257 atrial fibrillation, sciatica. Cardiotrophin CTF1
- (Ismail Elouafiq, not attending?)
- Steven Jonas

#### Planned agenda:

#### Panel discussion: "From individual to collective self-research"

How do people translate individual ideas and efforts to work that involves others? This can include shared & re-used methods, tools, and analyses, to aggregating data for collective insight.

We'll invite attendees to participate as a panel of ourselves, and we'll be recording the conversation to share everyone's questions and insights with others.

(For what we hope this will be like, see our recording of the recent panel discussion on February 24, Keating Memorial Self Research: Getting Started – challenges & advice)

#### Agenda:

- Note: this call will be recorded and shared publicly.
- Roll call
- Open Humans news: upcoming board elections
  - community seat + 2 board-elected (same pool of candidates)
  - o plan to share candidate form via email & blogpost later this week
- Panel discussion (see topic above)

## Notes:

- This call will be recorded and shared publicly.
- Note-taking is welcome but we won't focus on it let's focus on listening to each other.

# February 11 2020

10:00 PST / 13:00 EST / 18:00 GMT / 19:00 CET

Google calendar event link: <a href="https://tinyurl.com/ukcph8u">https://tinyurl.com/ukcph8u</a>

## Attending:

- Mad Ball
- Bastian Greshake Tzovaras
- Patrick Tagert (Patrick B's iPad)
- Nita Jain
- John Marlowe
- Steven Jonas
- (Marcel van der Kuil)
- Lubna Dajani
- James Littlejohn
- David Blackwell huFE0257 atrial fibrillation and sciatica.
- Gary Wolf
- Ben Creasy
- Liubov Tupikina
- Beau Gunderson
- Adrian Gropper

#### Agenda:

- Overview: Open Humans updates & topics for this meeting
  - Keating Memorial self research how it's going so far, etc.
  - Feedback to UN Committee for Human Rights on Article 27:
     <a href="https://docs.google.com/document/d/1cC\_l77ICljJ\_7R9B\_xte-50P00r-JDrPGzaA0W0CuS0/editor)">https://docs.google.com/document/d/1cC\_l77ICljJ\_7R9B\_xte-50P00r-JDrPGzaA0W0CuS0/editor</a>
     <a href="mailto:totalcolor: blue: blue to the properties of the prope

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- Open discussion please be invited to bring questions & topics! Especial...
  - Questions about your self-research ideas
  - Questions about "why" we're doing self-research & how it interrelates to other stuff Open Humans supports and does
  - Site features & wishlist items (anything about the site that's annoying or wish we had?)
  - o general Qs about Open Humans
- Please feel free to add potential discussion items below and tag them with your name
  - o Bastian: Should we also record the community calls? Would people find this useful?
  - Liubov: are there needs of making sort of open repository for time-series analysis of patients data (for well described data with metadata and with concrete questions)? E.g.like we do for chronic pain patients data analysis this is more to share methods in order to discuss their applicability for some particular data types
  - Role of data access control standards to empowering individual participation @agropper

## Notes

- Bastian's first question: Should we record our community calls? Would this be useful?
- Mad: we recorded our kick-off seminar for the keating research memorial, see <a href="https://blog.openhumans.org/2020/02/10/notes-video-from-our-self-research-kickoff/">https://blog.openhumans.org/2020/02/10/notes-video-from-our-self-research-kickoff/</a>
- Updates on Keating Memorial (details at <a href="https://www.openhumans.org/self-research/">https://www.openhumans.org/self-research/</a>)
  - o 59 people have signed up through Open Humans
  - Not all have posted an idea on the forum yet, here's a good place to say hi!
     <a href="https://www.openhumans.org/self-research/">https://www.openhumans.org/self-research/</a>
  - Feel invited to participate, even if you're new to all of this, we explicitly want to involve newcomers!
  - Have been sharing it more widely (e.g. on the quantified self forum)
  - o Might also want to share on Reddit, Steven Jonas might be the right person for it
  - Lots of self-research ideas and project logs are already on https://forums.openhumans.org/c/self-research/7
  - Might be worth to add 3rd forum category: For 'one-off' retrospective data analysis, e.g. like
    Bastian did for noise data (see
    <a href="https://forums.openhumans.org/t/tracking-hearing-sensitivity-over-the-day/195/5?u=gedankenstuecke">https://forums.openhumans.org/t/tracking-hearing-sensitivity-over-the-day/195/5?u=gedankenstuecke</a>)
- Feedback to UN Committee for Human Rights on phrasing and interpretation of Article 27
  - Paragraph 1 of Article 27 of the Universal Declaration of Human Rights in English reads:
     "Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits."
  - But... not all of the languages it is phrased as "share" where the clause "participate" is unclear in English but in other languages (Spanish, French, Russian) the word "participate" is applied directly to science.
  - A letter that can be signed by all of us is drafted here:
     <a href="https://docs.google.com/document/d/lcC\_l77ICljJ\_7R9B\_xte-50P00r-JDrPGzaAOW0CuS0/edit">https://docs.google.com/document/d/lcC\_l77ICljJ\_7R9B\_xte-50P00r-JDrPGzaAOW0CuS0/edit</a>
    - Mad: This links to comments & suggested changes on the document the UN committee is asking people to comment on https://docs.google.com/document/d/1iuAzDOKrmecPv32BoJ7sUBFwtnVryHFy/edit
  - Gary: This came up in the very first posts we made on Article 27 in the QS blog. Immediately a community member said 'i think you're wrong with your interpretation of this clause'. Was surprised that this came up
    - Gary: so I would've thought this was esoteric, and yet it came up right away. So I think it would be valuable to refer to the document. In our fundraising work we step away and say "it is evident that it's valuable to do this" without declaring the right; but I fully support Paul's effort here.
- Liubov: new to this community (so far have looked into a project with Bastian & Olivier regarding chronic pain data analysis)
  - Link to project: <a href="https://github.com/oliviermirat/MonsterMizer/">https://github.com/oliviermirat/MonsterMizer/</a> and <a href="https://www.monstermizer.com/">https://www.monstermizer.com/</a>
  - Would it be useful to have a repository of methods to use on time series data to analyze various variables
  - Mad: Is this on individual or group data?
  - Liubov: So far done on individual data, curious about group analysis
  - Bastian: are you looking for data itself or a place to publish methods so others can re-use them?
  - Liubov: how to share data analyses so they can be re-used by others in different contexts (e.g. an analysis done for chronic pain may use methods other folks can use)
    - e.g. I have an idea on how to explain it in a notebook

- Bastian: yeah, I think if you can make a notebook that's generic enough... e.g. it expects to have two columns in a CSV as input, you could share the notebook
- in Open Humans you can use this: <a href="https://exploratory.openhumans.org/">https://exploratory.openhumans.org/</a>
- o Gary: could I ask what you think the potential need is use case might be?
  - Liubov: imagine there's data on activity related to some symptom of disease and this analysis finds the optimal activity by correlating # of headache vs. activity
    - ... or "what causes what" when you have two time series
    - or "this does not cause X" and you can mathematically show that too
- o Gary: I think the current workflow would be...
  - to do the tracking & analysis on a one-off basis (you have to specify and adapt and modify protocol) and there will be an iterative process of discovery
  - then, if you feel like you have a strong signal or helpful analysis, do what Bastian suggests & share the notebook
  - then if someone tries using it, they may give feedback on it & you can help them adapt it. Think of the scaling process as starting with 1 person, more than 1 don't start by imagining a workflow supporting 20 people to start with, because you've under
- Benjamin Creasy: is there some way to work with AllofUs?
  - o Gary: I've followed them and my take is that they're very committed to a Big Data surveillance paradigm for discovery, to ask population-level questions
    - there's been glitches e.g. investments in a data management company that hasn't delivered promised analysis tools
    - What they're NOT doing: enabling you as an individual to connect your data to other subgroups and answer you own questions
      - it's something they'd want to do, but they're preoccupied
  - Adrian: I'd second what Gary said AllOfUs stated individual access to data is what would be innovative, and they haven't followed up on that at all yet. It's seemed like a bait and switch strategy to differentiate themselves from other biobanks.
  - o David: I've joined AllOfUs & helped family members join. I'm very sympathetic to the software issues here & encourage patience.
  - Benjamin: with the forum, the data isn't structured. "Cure together" was more structured.
     Personally I'm interested in studying Crohn's disease. Haven't weighed in, concerned a bit about privacy issues in having conditions.
  - o David: I'm also interested in inflammatory conditions.
  - Mad: You mentioned privacy issues with participation in the forum. I wanted to mention that you can create a pseudonymous account with Open Humans and the forum. I hope that helps to get around those issues a bit.
  - Gary: on the topic on crohn's, microbiome, and digestion: there's some expertise in the forum, especially on using functional measures an alternative to trying to master the -omic data (genome, microbiome) it would be great to see more projects & denser learning on the topic
  - Ben: Yeah, i might use a pseudonym. I generally post on this under my name but I don't want this to be the first thing to appear when searching for my name
  - Mad: There was a mention of indexing data and I want to point out that we're working on better supporting data types and their indexing. What we're doing on the Forum right now is prototyping this manually
- Adrian: Q about data access control standards I spent a large fraction of my time working on standards groups on acess controls to data in general. My focus is on healthcare, but the standards aren't healthcare specific. The interest of self-sovereign person is always never represented in those standards-groups. Typically participants are paid for by corporations. This will not change without e.g. governmental intervention, which only rarely happens. This is very different from policy interventions.

- David: I'm personally interested in this, something I'm familiar with is the Broad Institute working on policy/protocol for data sharing & agree it's very hard.
- Bastian: I think what we've been seeing in Europe has improved quite a bit since GDPR, and online corporations give access to your data and standardized according to the formats of their corporation
  - Adrian: not talking about the data model, but the access control aspect the ability for the individual to control and share access to that data
- Bastian: in principle GDPR supports portability (article 20)
  - Adrian: the issue with GDPR is the act of moving from principles to implementations is missing – subject to regulatory capture
- Mad: The issue of regulatory capture is a thing, this has been a focus of our work with MyData Global, together with e.g. Paul-Olivier Dehaye. But it's hard to advocate for changes if there's only hypothetical use cases. What we're trying to do with the self-research in the forums is trying to showcase some actual use cases of what people could do with those kinds of data.
- Adrian: think the MyData Operators meeting needs to have more people like the ones being involved in this group
  - Mad: Link to draft they're working on with MyData health <a href="https://docs.google.com/document/d/13CGdr0xPleErJxy4V3LLppC1VdsYijgrFXSDaS5do8k/edit">https://docs.google.com/document/d/13CGdr0xPleErJxy4V3LLppC1VdsYijgrFXSDaS5do8k/edit</a> in the #health-data channel in mydata.slack.com
- Dave: I'm interested in Nebula Genomics data, anyone familiar with it?
  - Patrick: I'm interested and tried it, and it seems like it's low coverage, like 0.4x coverage, and
     I'm finding big gaps a lot of imputation vs. the actual regions that were sequenced. So primarily imputed data.
- Mad: something I've been kicking around is wondering about creating a wiki
  - Bastian: something I'd like to see is enabling people within activities to interact with each other. not sure if a wiki is the way to do that... maybe we could automatically create an area in the forum for that activity & link to it
  - Mad: how would that work? would anyone be able to see it and post to it? only people in the project?
  - Bastian: I think anybody & would imagine people deciding whether to join a project based on forum interactions
  - Mad: it's possible to classify a category as only available to people in a "group" (and manage the group)
  - o Bastian: open is easiest, for sure & would address the main need I'm thinking
- Closing round

## January 14 2020

10:00 PST / 13:00 EST / 18:00pm GMT / 19:00 CET

Google calendar event link: <a href="https://tinyurl.com/su9eza9">https://tinyurl.com/su9eza9</a>

## Attending:

- Colette Andree
- Saba K
- Benjamin Carr
- Mad Ball
- Gary Wolf
- Richard Sprague
- Jakob Eg Larsen
- Jay Malik
- Nita Jain
- Jane I
- R Sterling Snead
- Jackie Horne
- Karolina Alexiou
- Jordan Clark
- Ernie Hershey
- JJ Ruescas
- Eric Jay Daza
- Christopher Wansing
- Ismail Elouafiq
- Kwok Ng
- Paula Leonova
- Rogier koning nobism.com
- Katarzyna Wac
- Stefania Druga
- James Littlejohn
- Ben Auchter

### Agenda:

- Introductions say hi to each other, share interests!
- News upcoming board elections
- Gary Wolf: thoughts about self-research & the Article 27 effort
- Mad Ball: upcoming plans for prototyping collaborative self-research

## **Gary Wolf Presentation Links And Notes**

I'll be discussing this piece: How to Make 10 Million Discoveries.

I'll summarize briefly and then we can have Q&A.

1. Definition of "Everyday Science"

Draft essay, <u>Personal Discovery Through Everyday Science: A Conceptual Framework To Guide</u> Research and Education by Gary Wolf and Martijn de Groot.

2. Examples of personal discoveries with everyday science:

**QS Show&Tell Library** 

## Mad Ball - planning a collaborative self-research project

- Presentation link: (Keating Memorial project) <a href="https://tinyurl.com/vrrqd7l">https://tinyurl.com/vrrqd7l</a>
- This link contains further links to other items, feel free to explore!
- Form to share your email to say you're interested:
  - https://forms.gle/Xo2SHzgzRNRsNGEUA
  - o doing your own project and/or contributing as an "expert"

#### Notes

- Mad: note that anyo
- aboynejames -- hello from scotland. working on open source & liberating data for the masses with peer-to-peer crypto
- Jordan Clark -- grad student at Northeastern researching Human Perception Ai interested in related tools QS tools with human chronobiome
- Karolina worked on data integrations with open humans, mostly data science
- Richard Sprague interested in quantified self, particularly interested in microbiome stuff
- Jay Malik accountant, not science/web, curious about how my body works
- Gary Wolf hi, I'll be presenting later & co-founder of Quantified Self
- Kat interested in studying quality of life and leveraging QS data for improving QoL
- Henry here., in North Carolina, Working on WhichWorksBest, n-of-1 toolkit for average folks.
- Kwok Ng post doc in Finland, interested in QS and open science.
- Mad announcement about upcoming board of directors election three seats will be up for election
  - o process is that all candidates names & info is public
  - o the list (unless someone opts-out) is first elected on by the community
  - o the board then selects two additional members from the same list
  - three year commitment, volunteer position, not much time (but as much as you want) –
     represents the top level of governance of the organization.
  - o if interested, think about it, share with anyone you think should be a candidate
- Gary sharing "everyday science" and Article 27
  - Everyday science: "using empirical methods to explore personal questions"
    - we debated should QS activities be called "science"?
    - the essence of science is the empirical methods it uses observations, formalized observations
    - "everyday" refers to the use of these methods to study questions that matter to you in your everyday life, things you care about as an individual
  - The name "Article 27" comes from the universal declaration of human rights, which guarantees a right to cultural participation, and specifically highlighting the right to science.
    - Has become relevant with "open science", "citizen science"
  - Why do this?

- Usually we think "research" is the job of professional scientists large randomized trials. But we're still left with the question "what's true for me?"
- Shared examples of projects
  - with Article 27, we want to figure out to how to scale up, to see 10 million discoveries made by individuals
  - From thousand up to now, target: thousand discoveries in two years.
  - Barriers: Access to data, instrumentation, power to act
- Questions & discussion
  - Eric Daza what are the barriers?
    - Gary: the last barrier I covered was the barrier to act
  - Jordan Clark at Northeastern one project they've worked on is something for understanding social dimensions <a href="https://sail.northeastern.edu">https://sail.northeastern.edu</a>
    - understanding the process in how to help people do these things rigorously?
    - Gary I'd love to work with you to model and understand the process.
    - In QS we've modelled "what is a discovery" with the show&tell questions, but the way has always been around a talk they'll give and reflecting backwards.
      - What if we make it easier to document projects as they go?
      - Maybe this documentation process structure can help, Jordan it'd be great to have you involved in co-creating this
  - aboynejames agree the "scientific method" needs to be updated. comparison to blinded trials: I've been underwhelmed by how much that has achieved for mankind.
    - Gary: thanks I totally agree. When I talk in clinical/scientific contexts, this is a very radical view. Maybe surprising. I think they are aware of the limits privately, but reasons for defensiveness.
    - questioning relevance, data quality, temporal resolution those are issues with clinical research too
  - Richard Sprague
    - I work in startup spaces. and in software there are so many ideas that are just "put out there, see if people want/use it" and some things take off
    - I feel like there's so much opportunity missed with everyday science that's being missed right now
    - Gary: something we're interested in along with open humans, figuring out what are the foundational resources for enabling these scale-ups. And one way to find those, is by doing our projects.
      - o I'd love for you to take a look at what we're building, potentially use it, and think about how it can scale up for commercial approaches
    - Richard: I think about case studies, being able to easily see one-off examples of what someone did & be inspired by them
      - Gary: as we went through our show&tell archive, and have been learning a lot about the cultural structure of these projects. We're learning a lot about the shareability – and lack thereof – about the process and tools level. How to structure projects such that it's findable and people are learning from it.
  - Kwok first meeting but have been on the slack channel, been great to listen to everyone – question/clarity: when we look at trying to track people's projects, making them shareable, meaningful, things they can try that others did... what I'm not familiar with is that kind of "platform".
    - there is google of course. wikipedia can be searched, can find things there.
    - what is considered an entry and not an entry? how is it structured?
    - Gary: this has to do with how to structure the knowledge

- e.g. it could be about the subject of what you researched (e.g. effect of alcohol)
- but what if it has to do with the tool (how to use data from an Oura ring), and that contains a solution that's useful to me (for a different subject)
- o so there's multiple dimensions, but we think there is structure
- and there's places people already share this knowledge, we think about what to do alongside those things
- Jordan question around "what would a pilot look like?"

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- Keating Memorial Project Idea
  - Collaborative Self-Research
    - In honor of
    - Advocate for patient data access
    - Exploring his own data and sharing it with others
  - Basic Format
    - Forum based
    - Self-Research category
    - Private groups
    - Start a post about your own idea/project
      - -ask for help
      - -Share insights and updates
      - -Get feedback

#### Expert support

- Via Webinars and via forum posts
- Share report by July 13
- Project timeline
  - Jan. 20-27: Share Call to Action to join group
  - Feb. 3: kick-off webinar
  - Feb. 17:
- What Qualifies as Self Research?
- o Open Questions: Communication Channels
  - Forums
    - "Project logs"
    - Not just "Project logs"
  - Group Video chats
    - Webinars
    - "Open Office Hours"
  - Chat Room
  - Private vs Public
    - Project logs private to a group
    - Chatham House Rules
- Expert Support
  - How do we know who is an expert?
  - How to provide expert support?

## December 10 2019

10:00 PST / 13:00 EST / 18:00pm GMT / 19:00 CET

Google calendar event link: <a href="https://tinyurl.com/wxja8sl">https://tinyurl.com/wxja8sl</a>

## **Attending:**

- Mad Price Ball
- Bastian Greshake Tzovaras
- Karolina Alexiou
- Cliff Vachon
- Gary Wolff
- aboynejames
- R Sterling Snead
- Paula Lenova
- Sean Cameron
- Katarzyna Wac
- Benjamin Carr
- Liubov Tupikina

## **Agenda**

- Welcome & introductions
- Invited speaker: Rogier Koning Nobism project & cluster headache community
  - https://www.openhumans.org/activity/nobism/
- Invited speaker: Karolina Alexiou GitHub data source & notebook
- Other stuff: ideas, etc.
  - Bastian: Has anyone tried Glucose monitoring?
- Open Humans feature: generic file uploads & DataTypes
  - o Generic file uploader: <a href="https://upload.openhumans.org">https://upload.openhumans.org</a>
  - Using DataTypes a new way to classify data, instead of "by project that added it".
  - Example iMoodJournal data (mood tracking)
    - About / upload: <a href="https://upload.openhumans.org/upload?datatype\_id=20">https://upload.openhumans.org/upload?datatype\_id=20</a>
    - Notebook using this data: <a href="https://exploratory.openhumans.org/notebook/75/">https://exploratory.openhumans.org/notebook/75/</a>
  - Example Apple watch environmental noise upload:
    - About / upload: <a href="https://upload.openhumans.org/upload?datatype\_id=21">https://upload.openhumans.org/upload?datatype\_id=21</a>
    - Notebook using this data: <a href="https://exploratory.openhumans.org/notebook/77/">https://exploratory.openhumans.org/notebook/77/</a>

## **Meeting notes**

- Intros
- Rogier Koning
  - Cluster headache patient called "suicide headaches" one of the worst pains one can have
  - Tried many treatments, realized I hadn't learned from these over years so I started tracking, using excel and (physical) notebooks, and apps. None of them really worked
  - Apps don't track the things of interest, e.g. alternative treatments, and no way to get the data to analyze them

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- Wanted a simple button to press to register an attack, as its time critical. Expanded from there: An app with lots of buttons to collect the relevant data
- Info about project: <a href="https://www.openhumans.org/activity/nobism/">https://www.openhumans.org/activity/nobism/</a>
- Observed effectiveness of treatments that work might be coincidence, needes to compare interventions with others. Now a group of patients that collect data through Open Humans.
   The code academy students help analyzing the data and produce monthly report
- DEMO OF CODE ACADEMY REPORTS: https://nobism.com/ubiqum/download-cluster-headache-reports/
  - Timeline, shows when people have their attacks, duration & intensity
  - Compare treatments and interventions and compare visually if there is a correlation to attacks & intensity
  - Currently working on further data visualizations to see evolution over time, combining both frequency and intensity of attacks
- Karolina
  - Built a GitHub connection to Open Humans at https://github.openhumans.org/
  - o Syncronizes all of your contributions to code
  - Notebook to explore it at <a href="https://exploratory.openhumans.org/notebook/74/">https://exploratory.openhumans.org/notebook/74/</a>
- Open Qs / chat
  - Bastian: experiences with CGM? I just ordered two freestyle libre sensors
    - Katarzyna: I've been using mine for two years. Have learned various things about impact of foods I thought were healthy, sleep deprivation.
      - to get data from the freestyle libre, have to get it via a computer app
      - Bastian: did you try using the mobile app to get data?
      - Kat: a student said it works
- Mad & Bastian: shared the file upload & new DataTypes format for managing data
  - o motivations are to support diverse data for uploads
  - o and to separate the "type" of data being managed from the project source
    - multiple projects may produce the same "type" people want to share
    - one project may produce multiple types, and people only want to share one type
  - Bastian: shared a notebook demonstrating the use sound data with passive GPS
    - Could also use Google Location History
    - Ben: Google Location History switches to only keeping the last 18 months of data, so we need to support appending data to existing files
  - o Rogier: these notebooks are too hard for non-experts, are there plans for easier tools?
    - Bastian: one thing we're hoping to implement is "voila", a project which hides all the code in notebooks! this could make running notebooks much more user-friendly
- More open Q;
  - Rogier: but can we have a more secure method of sharing data, where the data is in a database and individuals grant access to it's use without access to the data itself?
    - aboynejames: this is an area I work in and it's important to recognize this level of security is something people have been working on, and it's very difficult ipfs is an example, which has been funded with hundreds of millions of dollars.
      - as an additional note related to data types: when data is end-to-end encrypted, an underrecognized problem is the one of understanding what data type the data is
    - Bastian: Sage Bionetworks is supposed to support this sort of thing, and has an ideal scenario with highly standard data, and from what I've heard it can still be very difficult, e.g. to review and ensure an algorithm someone submits isn't (potentially accidentally!) leaking information from the data it's being run on.