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 Open Humans Community & Self-Researc...

## Open Humans Community Calls And Self-Research Chats - 2021

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, first 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 [Steven Keating Memorial Self-Research Project](#) 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/j/196519106> Passcode:922125
3. **Open Humans Community calendar:** <https://tinyurl.com/sfglmx8>  
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/y4djoj6d>  
Editing this document:
  - add your name and/or ideas to an upcoming call.
  - The document is editable, so please be invited to contribute to note-taking!
  - Archive of previous notes: <https://tinyurl.com/wprwl2b>

We also use Slack a lot to chat – you're welcome to join! Get access here: <http://slackin.openhumans.org/>

**Meeting links:**

[December 16 \(Self-research Chat\)](#)

[December 09 \(Self-ResDecember 16 \(Self-research Chat\)earch Chat\)](#)

[December 07 \(Community Call - open / no agenda\)](#)

[December 02 \(Self-Research Chat\)](#)

[November 25 \(Self-Research Chat: canceled for Thanksgiving\)](#)

[November 18 \(Self-Research Chat\)](#)

[November 11 \(Self-Research Chat\)](#)

[November 04 \(Self-Research Chat\)](#)

[November 2 \(Community Call\): Self Research Motivations](#)

[October 28 \(Self-Research Chat\)](#)

[October 21 \(Self-Research Chat\)](#)

[October 14 \(Self-Research Chat\)](#)

[October 7 \(Self-Research Chat\)](#)

[October 5 \(Community Call\): Quantified Flu paper](#)

[September 30 \(Self-Research Chat\)](#)

[September 23 \(Self-Research Chat\)](#)

[September 16 \(Self-Research Chat\)](#)

[September 9 \(Self-Research Chat\)](#)

[September 7 \(Community Call\): AutSPACEs](#)

[September 2 \(Self-Research Chat\)](#)

[August 26 \(Self-Research Chat\)](#)

[August 19 \(Self-Research Chat\)](#)

[Keating Memorial Show&Tell Talks](#)

[Details](#)

[Announcement \(post anywhere\)](#)

[August 5 \(Self-Research Chat\)](#)

[August 3 \(Community Call\)](#)

[July 29 \(Self-Research Chat\)](#)

[July 28 \(Tech Meetup\)](#)

[July 22 \(Self-Research Chat\)](#)

[July 15 \(Self-Research Chat\)](#)

[July 14 \(Tech Meetup\)](#)

[July 8 \(Self-Research Chat\)](#)

[July 6 \(Community Call\)](#)

[July 1 \(Self-Research Chat\)](#)

[June 30 \(Tech Meetup\)](#)

[June 24 \(Self-Research Chat\)](#)

[June 17 \(Self-Research Chat\)](#)

[June 16 \(Tech Meetup\)](#)

[June 10 \(Self-Research Chat\)](#)

[June 3 \(Self-Research Chat\)](#)

[June 1 \(Community Call\)](#)

[May 27 \(Self-Research Chat\)](#)

[May 20 \(Self-Research Chat\)](#)

[May 18 \(Tech meetup\)](#)

[May 13 \(Self-Research Chat\)](#)

[May 12 \(Tech meetup\)](#)

[May 06 \(Self-Research Chat\)](#)

[May 04 \(Community Call\)](#)

[April 29 \(Self-Research Chat\)](#)

[April 22 \(Self-Research Chat\)](#)

[April 15 \(Self-Research Chat\)](#)

[April 08 \(Self-Research Chat\)](#)

[April 06 \(Community Call\)](#)

[April 01 \(Self-Research Chat\)](#)

[March 25 \(Self-Research Chat\)](#)

[March 18 \(Self-Research Chat\)](#)

[March 11 \(Self-Research Chat\)](#)

[March 09 \(Community Call\)](#)

[March 04 \(Self-Research Chat\)](#)

[February 25 \(Self-Research Chat\)](#)

[February 18 \(Self-Research Chat\)](#)

[February 11 \(Self-Research Chat / Keating Memorial Kickoff\)](#)

[February 09 \(Community Call\)](#)

## December 16 (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: <https://tinyurl.com/2t77jst3>

Attendees:

- (Mad Ball)
- Dan B
- Gary Wolf
- D G
- Bastian Greshake Tzovaras
- Enric

Agenda topics:

- Enric: share update on his smartphone use experiment and its relation to autoethnography
- Dan: got diet & weight change data ready to present
- Katharina: small progress update on Wiki
- Gary: question about another QS conference
- D G: small article for discussing a wiki

Notes:

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## December 09 (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: <https://tinyurl.com/2t77jst3>

Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- Gary Wolf

- Tahl Milburn
- Dan B
- Joyce Waterhouse
- Enric Senabre
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#### Agenda topics:

- Tahl Milburn wants to show his tahl.io dashboard.

#### Notes:

- Skipping go around to start with Tahl sharing as he needs to leave in 15m
- Tahl:
  - Full walkaround would take more time than we have
  - Shared an earlier version a couple months ago; this is a more "final" version now.
  - LIAM = life information management system; three major aspects
    - past / present / future: LifeChronical, LifeState, LifeConsole
  - Design uses cards to be mobile friendly. Data covers nearly 9000 days worth. Most items don't change, but other items are fairly "live" (updating every 3 min).
  - There's a "Log-in" that's used because there is \*some\* (not much) info that's kept private or has "dummy" info in the public version (e.g. this is done for financial info).
  - Gary: I'm wondering, what have you learned?
    - Tahl: it feels like much of this is beyond/outside learning. One item that stands out for me is for example the "significance" events, understanding what sorts of things are significant for me. But in general it feels like "life management" at this point, rather than learning at this point.
    - Gary: what are some things you learned in the last week for example?
    - Tahl: for example, photos I take are processed and tagged by Google AI, and this is interesting. I like reviewing what I've been doing in the recent past, and seeing for example that I've had a diversity of experiences recently. Sometimes this reflection prompts new ideas of things to do, I reflect and think differently on what I experience.
  - Tahl: I'm often asked "how long does this take to do?" The website took a long time, a year; maintenance is low though, maybe 10 minutes a day.
  - Enric: I see a lot of modularity combined here. What's behind the ordering on which things go in what section e.g. chronicle vs state.
    - Tahl: with lifestate, I ordered the first items as "not personal" types of things, more impersonal. (Location, home status.) Second row is much more personal. The three cards here reflect my own model of nine factors important in life, in "personal", "functional", and "interactional" categories. And a third row that's less personal, of things I'm experiencing and doing.
    - Enric: in the former section, there's travel and people/experiences, these are personal as well? Tahl: yes, but those are about the past rather than the "present".
  - — (Tahl left) —
  - Mad: one thing it has me reflecting on is the aspect of public data, in particular how it intersects with any potential concerns or risks posed to others explicitly or implicitly represented in data (e.g. partners, other family). In particular I've had a fair amount of experience with people that do radical sharing, and it's interesting to see how things actually play out (rather than speculation about potential risks).
  - Joyce: it's interesting to have so much data collected such that one could in theory create a more accurate "autobiography" – because human memory is unintentionally flawed!

- Gary: it makes me think about just saving, banking this data somewhere.
- Bastian: an interesting aspect for me is \*why\* make all this data public.
  - Gary: I think one of the main benefits he sees is this. He's sort of "performing his life" for a small audience that he cares about.
  - Mad: I think there's a counterpoint where people avoid having their "authentic selves" on the internet because it becomes a performance of themselves, and creates a barrier to being their authentic self.
  - Enric: the QS personal archiving reminds me of Alberto Frigo "life stowing" which is more artistic
    - <http://diva-portal.org/smash/get/diva2:1090316/FULLTEXT01.pdf>
- Mad: Gary relates that Tahl has developed habits now for tracking, doing the things that integrate with this ... and I'm curious how it "started", what the initial interest and impulses were, and then what positive feedback sustained it to become habitual and a lifestyle.
  - Gary: I think it branched out from IoT interests.
  - Bastian: reminds me of Miguel's comprehensive data.
- Mad: I wonder what would happen if Tahl "stopped" doing it, had it break or be torn away – maybe what he anticipates feeling – which reflects what sort of need(s) he may feel this serves.
- Bastian: I was struck by some things as "private" that I wouldn't be so uncomfortable sharing (e.g. financial) versus stuff I'd be much more wary of – e.g. SMS messages (!)
  - But the SMS aren't updated since August... I wonder if these are mock-ups, or things went private.
- Joyce - unrelated, I had a question to throw out - I was researching, interested in electrical stimulation and what its used for. There's something called cefaly for migraines, and something called alphastim for anxiety and depression. Even found an NHS study that claimed cost/benefit of that treatment would save a lot of money. Curious if anyone has some knowledge about these.
  - Mad: I've heard of ECT, which is more dramatic... it looks like there's CES which was developed as a much milder version
  - Bastian: also reminds me of transcranial magnetic stimulation
  - Reflecting that alpha-stim seems to require iprescription in US but not elsewhere
    - reflecting on regulations regarding medical treatments and devices... exact language matters so much. e.g. you can say "reduce stress" but "reduce anxiety" triggers regulatory concerns. Or "food sensitivity" is considered outside medical regulation.

# December 07 (Community Call - open / no agenda)

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: <https://tinyurl.com/376na2bk>

## Attendees:

- Mad Ball
- Dan B
- Bastian Greshake Tzovaras
- D G
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## Notes:

- D G: is there any potential for the org hiring a statistician?
  - Mad: extremely unlikely; the org is currently paying people as independent contractors, typically for specific tasks
  - Bastian: I think one question would be, what would one hire someone for?
  - D G: interested in determining whether one variable is correlated with, influences another
    - Been thinking about how to handle time series in particular, because neighboring timepoints are going to be correlated.
    - Bastian: note a statistician is commonly going to say they were consulted "too late", i.e. "if
- Paper on how 70-ish teams of researchers test the same hypothesis with the same data and find very different results: <https://osf.io/preprints/metaarxiv/cd5j9/>
- The gorilla hidden in the data:  
<https://genomebiology.biomedcentral.com/articles/10.1186/s13059-020-02133-w>

# December 02 (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: <https://tinyurl.com/2t77jst3>

Attendees:

- Mad Ball\*
- Bastian Greshake Tzovaras\*
- Dan B\*
- Gary Wolf\*
- Joyce Waterhouse (just listening today)
- Katharina Kloppenborg\*
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Agenda topics:

- Gary: Starting new round of experiments arrhythmia
- Katharina: some wiki updates

Notes:

- Katharina: wiki updates:
  - Added templates to mark article might be something that could be expanded or improved.
    - Stubs: (“{{stub}}”) and citation needed “{{citation needed}}”
  - Front page now lists to “wanted pages” and “stubs” that could use some expansion
  - Added pages for self-research chats from september until now, added metadata to topics we talked about, to get a ranked list of topics we generally are interested in
  - Policies that diverge from Wikipedia:
    - original research OK
    - (new?) OK to link "User:" pages as "people", c.f.  
<https://wiki.openhumans.org/wiki/User:Gedankenstuecke> linked by this project:  
[https://wiki.openhumans.org/wiki/Sleep\\_recordings:\\_Oura\\_vs\\_Fitbit](https://wiki.openhumans.org/wiki/Sleep_recordings:_Oura_vs_Fitbit)
      - Still unclear whether we want "main" vs "User:" namespace pages for individuals, whether these are "different", an individual has both, etc. But it seems in practice that it feels "weird" or uncomfortable to have to create a formal page about oneself when documenting one's own project.
  - Updated category page templates (Tools, Topics, Projects, People). Now you can just click on the respective category overview site (also in the side menu), and you find links on the top to a form that helps you create this page with all the relevant templates and metadata. The content of the pages is not prestructured otherwise.
- Gary: thinking about "problem" / design formulation about a new effort regarding arrhythmia self research, which I've been doing since May 2020
  - In these phases, one of the most confounding issues has been that the arrhythmia symptoms come and go in multi-month cycles. I'm skeptical that anything I'm doing as an intervention is causing these.



- Based on biomedical literature, have a suspicion about "why" this pattern exists: I think there's strong feedback loops. Once they get going, they promote keep going. Then something causes it to go away, maybe a shock to system, and they're gone until they start again.
- Not uncertain about how to track arrhythmias now; but unclear what questions to formulate, or how. e.g. there's a lot of things I could track, e.g. sleep – but is it useful? e.g. I might know "sleep contributes 6%, eating before 8am contributes 8%..." will that help...?
- Mad: it sounds like you don't want a mild effect on better/worse, but what will trigger a state change so you're back in the state where they aren't feedbacking to have a sustained issue over a period of weeks or months.
  - Gary: right, so I don't really care about reducing by 5%, I want to switch back.
- Bastian: what patterns do you notice?
  - Gary: maybe some seasonal correlation; lasting weeks to a couple months.
- Mad: do you have hypotheses about the state change?
  - Gary: I do think that overall health is a factor.
  - Gary: I noticed tremor and arrhythmia are interrelated, and I know tremor is influenced by overall wellbeing issues, and I suspect the arrhythmia may also be.
  - Gary: the way Oura and Marco Altini's app seem like they're using heartrate as proxy for holistic wellbeing in the way I think these are related to that.
- Mad: at the risk of asking the obvious, you try to improve this overall wellbeing to try to make it go away?
  - Gary: I'm always doing that, of course. And honestly, I'm not clear on how it was falling short?
  - Mad: it sounds like, you thought you were doing a good job, and yet...?
  - Gary: yes, and it's really unclear what intervention to make.
- Dan: is there something you notice happening before it gets worse?
  - Gary: No... and I feel like it's the most sensitive thing. It happens before I notice other things, and prompts me to reflect on them.
- Gary: it has me thinking about complex chronic conditions more generally; e.g. when working with Azure Grant on frequent cholesterol measures and circadian influences... there's a theory in circadian community that "instability" in that cycle is an indicator of other issues. And that lack of stability increases with age.
  - Mad: unfortunately that doesn't mean it's a cause; it could be a related effect of the same underlying aspects of age
- Bastian: I wonder what causes the cycles to break – if it's such a dramatic decline.
  - Gary: I like this idea; instead of looking for the trigger, but looking for the anti-trigger. The question becomes ... what should I add to the tracking so I can potentially find what changed, what caused it to *stop*.
  - Bastian: keeping a diary the day it "stops", "gets better"
  - Mad: the time it goes away, it's the hardest time to notice
  - Gary: luckily that is something that's clear because I'm doing very detailed tracking...
    - Keeping track of what daily incidence is, could notice when it drops below & a good period is starting.
    - Could try to engage in interventions deliberately to see if any of them turn out to be the magic formula. (But then I know that they eventually go away so maybe it wasn't due to whatever I happened to try at that time.)
  - Mad: I think there isn't anything wrong with doing eight things at once. You know that it might only be one or two or three of those things, and that's OK. All you care about is that you found something that works, not that you've proven which one it is.
- Bastian: the cluster headache community found that headaches stop in 15 min if they do oxygen flow therapy – reminded of this; somehow someone must have found this by trying lots of different things.

- Gary: that gives me a concrete idea of something to try... Andrew Ahn's HRV tutorial refers to the control one can deliberately exercise in parasympathetic nervous system through reduction in breathing rate. This increases vagal nerve activity which suppresses heartrate. It feels like an equivalent of trying oxygen therapy – very deliberate intervention, wonder if it would have an effect.
  - Maybe/even in the short term. With the feedback loop; in mice, they've seen that you can increase the signals in these nerves by "priming" arrhythmias. The theory might be, maybe you could break a cycle immediately.
- Gary: I think what I'm planning are three things to try...
  - Increasing exercise
  - Reducing coffee
  - Trying the breathing exercises
  - And not try to do these one at time.
- Mad: the new oura ring is good? the new gen3 thing?
  - Bastian: didn't see much difference from previous. it does have more info about heartrate throughout the day (not just overnight). The big claim about O2 saturation is "in development" and hasn't been launched yet.
  - Oura is planning to launch a subscription for gen3 ... in theory there's a half year "free"
- Katharina: is there any good tracker that doesn't have a subscription model now?
  - Dan B: I think it depends on what you want to track. e.g. the Apple Watch doesn't have one, but has limited capabilities.
  - Bastian: I think Fitbits have a premium but it's mostly for guided workouts; most of the actual metrics don't require subscription.
  - K: what does Oura have that Fitbit doesn't? B: it used to be the temperature sensor, but I think newer fitbits have that as well. (And there's a ring vs. wristband difference.)
  - Bastian: notably the CEO just stepped down and there's an interim CEO (for Oura)
    - Gary: that's rarely a good sign, I hadn't heard about that. :-/ I know he was a prime driver in raising funds, but there's been concern about how to make money.
  - Dan: does it have more heartrate data? Bastian: I haven't seen additional data via the API... there used to be a different API they made for "teams" (academic studies) that had more data.
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November 25 (Self-Research Chat: canceled for Thanksgiving)

**No meeting on November 25, as it is Thanksgiving in the US. Happy turkey day to everyone who celebrates!**

# November 18 (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: <https://tinyurl.com/2t77jst3>

Attendees:

- Bastian Greshake Tzovaras\*
- Mad Ball\*
- Dan\*
- Joyce Waterhouse\*
- Katharina Kloppenborg\*
- D G\*
- Enric\*

Agenda topics:

- Joyce: have a brief update about EEG recording
- Mad: tracking "stress"? curious about methods
- Wiki updates, ideas

Notes:

- Next week is (probably) cancelled: Mad and Bastian both anticipate not being able to attend (as such, who would act as "host" account is unknown).
- Joyce EEG update:
  - This is the second time I've had to get a replacement for the Muse band, the sensors wear off.
  - There's one finding I feel I can say with some level of confidence, related to watching the EEG as well as heartrate while eating foods. I don't see that the heartrate and EEG are very correlated.
  - One thing I focus on that seems more significant is that "delta waves" which are supposed to be related to sleep & a hypothesis that "intrusion" of delta waves while awake (and conversely alpha waves during the nighttime) relates to chronic fatigue syndrome.
  - Delta waves tend to go up more often during a meal, while I'm eating. Now they don't go "up" as much while eating. Used to go over 120, now not over 100. I think these may relate to a reaction to the food (less reaction to the foods means delta waves don't go up as much?). But also that maybe there are different types of reactions, some affect heartrate, some affect delta waves.
  - Dan: What are you using for EEG? I've had issues with sensors in the past...
    - Joyce: Using the "Muse S" headband, but needed to have the headband replaced twice as the sensors would go off
    - Dan: haven't tried that one, tried the Emotive and non-consumer devices
  - Joyce: regarding artifacts while eating, I know that while chewing it affects it a lot; I try to pause and observe during that pause. I don't see that it's very affected by standing, sitting, even talking -- even eating foods that aren't too "hard" don't seem to have a major effect.
  - Bastian: I think the consumer devices may have gotten very good at detecting artifacts and "throwing it out" -- it's not that the sensors no longer pick it up.
- Mad: generally curious about tracking stress, not just devices but also logging (e.g. daily logs, journaling).

- Joyce: about stress, it's generally understood to correlate with effects on heartrate, higher heartrate. also effects on stuff like sleep. I've been thinking about it in terms of reframing the app I work on, how to discuss food sensitivity reactions... effects on heartrate, mood, sleep. Can all lead to effects on mental state.
- Mad: general observation I've seen with qualia tracking is that it's hard to track "levels"... most useful is to relate to previous days rather than hope for an absolute value you "know" is correct.
- Dan: I think it's also useful to record "what you're worried about" because you can go back and evaluate it.
- Dan: I also wonder how people develop these scales get developed ... using likert scales.
- Bastian: sometimes there's time periods and frequency, e.g. "in the last month" or "frequently". Mad: also functional disruption, e.g. "are you unable to perform daily tasks".
- Joyce: one comes across tests that are "validated", not sure how that happens...
- D G: I use mysymptoms a lot, and having concrete "impacts" (affects functions) tends to be the most useful.
  - Dan: examples? D G: e.g. how often it disrupts my work. I find whenever I don't use a concrete scale regarding functional impact, it "drifts".
- Joyce: when I'm doing it, I think of the "highest level" as absolutely obsessive thinking; next lower is mind jumping around a lot, unable to stop it... then next is I can turn my mind away from it but it comes back...
  - Mad: that's interesting as an executive function impact description
- Enric: when I was using daylio, I recall losing confidence in whether the data was actually telling me anything useful about mood, stress, etc. Regular journaling or diary, more topic specific with descriptions... I don't know what sort of analysis one could use to understand it.
- Mad: one dissatisfaction I have with functional disruption is that one may learn to avoid behaviors that experience the disruption (rather than the underlying issue being less severe)
- Bastian: ecological momentary assessment comparisons...  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6526071/>
- Wiki updates - meta stuff
  - Mad: email is working now
  - Mad: created a first draft of an "about" page:
    - <https://wiki.openhumans.org/wiki/PersonalScienceWiki:About>
    - note I made a statement that governance is vague, because I think it is -- listed the "communities" of people involved, trying to be transparent while not claiming anything that doesn't exist
  - Katharina: created an "open issues" page and "brainstorming"
    - [https://wiki.openhumans.org/wiki/PersonalScienceWiki:Open\\_Issues](https://wiki.openhumans.org/wiki/PersonalScienceWiki:Open_Issues)
    - <https://wiki.openhumans.org/wiki/PersonalScienceWiki:Brainstorming>
    - Enric: on these pages I get confused about whether to add somethings on the page itself, or adding it to a "talk" page.
      - Mad: the project page may have user sigs while the "talk" page goes unused, e.g.  
[https://en.wikipedia.org/wiki/Wikipedia:Articles\\_for\\_deletion/Log/2021\\_November\\_18](https://en.wikipedia.org/wiki/Wikipedia:Articles_for_deletion/Log/2021_November_18)
  - Katharina: updated the landing page based on a suggestion from Enric
    - [https://wiki.openhumans.org/wiki/Personal\\_Science\\_Wiki](https://wiki.openhumans.org/wiki/Personal_Science_Wiki)
  - Katharina: made another try at recording "self research chat" notes in the wiki. I think this is likely too much work...
    - instead maybe a small stub like this...
    - [https://wiki.openhumans.org/wiki/2021-11-11\\_Self-Research\\_Chat](https://wiki.openhumans.org/wiki/2021-11-11_Self-Research_Chat)

- Mad: I'd rather not have the zoom join info included in other places; it should stay in one place to (1) reduce risk of malicious joining (zoombombing), (2) just one place to update/change that link in case malicious issues arise (and we need to change our address/info)
- Mad: also I think this is getting into a non-meta thing; don't know that people have much feedback on desired content for a specific page like this (but should say "I don't want this!" if there's undesirable content)
- Katherina.: another meta issue is e.g. on this page [https://wiki.openhumans.org/wiki/Why\\_is\\_My\\_Blood\\_Sugar\\_High%3F](https://wiki.openhumans.org/wiki/Why_is_My_Blood_Sugar_High%3F)
  - this page is filled with some automatically generated template
  - meta is ... there is automatically generated "template" stuff. is it "too much"? how should it look - right now it looks like manually added content
    - Mad: I would prefer anything that doesn't look manually added, table formatting
    - Bastian: maybe something in it could also flag it, like "this article belongs to articles in this category"
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# November 11 (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: <https://tinyurl.com/2t77jst3>

Attendees:

- Bastian Greshake Tzovaras\*
- Katharina Kloppenborg\*
- Gary Wolf\*
- DG\*
- Joyce Waterhouse\*
- Steven Jonas\*

Agenda topics:

- Changes/Updates to the Wiki

Notes:

- Updates to the Wiki
  - Gary made two project pages:
    - [https://wiki.openhumans.org/wiki/Why\\_is\\_My\\_Blood\\_Sugar\\_High%3F](https://wiki.openhumans.org/wiki/Why_is_My_Blood_Sugar_High%3F)
    - [https://wiki.openhumans.org/wiki/Memorizing\\_My\\_Daybook](https://wiki.openhumans.org/wiki/Memorizing_My_Daybook)
    - Steven's also has all the metadata that is in the QS S&T database
  - Steven: A motivation for me to write blog articles etc is that they might be linked somewhere, e.g. on reddit, where people read and discuss them. This could also be a motivation for writing wiki articles.
    - Gary: For me it is also motivating if somebody prompts me on the forum about a project that I made
  - Gary: Metadata on the wiki is important (like related topics)
    - Steven: Yes, like on compilation pages on Wikipedia. Something like, all the projects that use brand x tracker
    - DG: link to wiki in forums and interact in forums but update wiki
    - DG: Wiki needs crosslinks? So if a page is linked in another page it should somehow be noted that way in the linkee page. I added Seth Roberts project to "interesting results" wiki page but nothing happened to the seth roberst project page.
    - DG: I actually found reading the report easier than listening to the video of Jonas' SRS project.
  - Gary: If I think about the impact the wiki could have, I think about the latent energy that exists - projects and people in the community. This could be leveraged at some point if we want to give the wiki a "marketing push"
  - Gary: A request that we often get is to explain things that people don't know how to do, e.g. how to calibrate blood glucose trackers, or exporting data from fitbit
    - Katharina: Knowledge like this could become its own category, e.g. "processes"
    - Gary (or Steven?): Or "how to's", based on particular projects, but updated - the person who made a project might have "hacked" it, and today there is new knowledge or new tools, so one could make how to's based that are based on projects, but easier for others to replicate

- Gary: Thinking about why self researchers would use this wiki. I would use it if it was a more efficient way to make use of the knowledge that is around me/in the community. The community is very small at the moment, we could think about using it for ourselves at the moment, requiring people to become members
  - Steven (or Bastian?): Because the community is so small, this is probably not necessary, there won't be too many people contributing now, just creating an account should be enough, no other restrictions
- Other type of content: links to research articles on a given topic, e.g. HRV
- Book club/Journal club on research papers related to QS/PS topics
- How-tos based on particular projects
- Other content types: negative results
- Dan: It would be good to have content to help people who identified a problem, but who then don't know how to start
- Dan: I have a lot of domain knowledge on diet tracking and using short cuts on my iPhone for that
  - Bastian: This might be very useful, because I don't know many other people who use these short cuts for self tracking, they are rather used for smart homes
  - Bastian/Gary (?): Diet tracking is hard, people tend to give up after 3 or 4 months
  - DG: I didn't find diet tracking that hard. Try bitesnap?
    - Gary: Bitesnap - I didn't know about this!
- Dan: Having the possibility to reach out to people who have the knowledge you need would be great.
- Gary: It would also be possible to reach out to communities with specific interests, e.g. diet tracking, who are experts in their field but not in our community.
  - D G: so every tool set or "what is being tracked" page should include a section on communities who have to track that ..
- Gary: We often reached the stage of finding out what could be useful, and making some examples, but then moving to the next stage is hard, because you need to have actual community members test and work with it
- Gary: Focussing on the social context and motivation is important
- Steven: I think what would be useful in the project category is the "What did you learn" section, as well as having the possibility to show all the visualisations one made (because that is a restriction in the forum [Kat: I don't know if i understood that right, it is only possible to display a limited number of images in the forum?])
- D G : Mad balls notes on meetings could be compiled summarized and added to the wiki.
- D G : wki the tools you use
- DG: change of subject wiki needs a template for what can be tracked? Heart rate for example? That may be where the tool sets and common procedure tutorials should actually go.



# November 04 (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: <https://tinyurl.com/2t77jst3>

## Attendees:

- Mad Ball\*
- Bastian Greshake Tzovaras\*
- Dan Stutzman\*
- Dan B\*
- Erik Kiaer\*
- Gary Wolf\*
- Enric Senabre\*
- Rick Roy\*
- Joyce Waterhouse\*
- Katharina

## Agenda topics:

- Wiki
  - Mad: brainstorming individual pages
- Bastian: could share apple data export (but after wiki)
  - Gary: I'm curious about this
- 

## Notes:

- Dan B: regarding the wiki, how does this compare vs "Roam" (pro/con)
  - Mad: Gary has assigned me "why wiki" and I think this would/should be something it would address
- Erik: new to this meeting, have tracked a variety of things. Interested in learning "how do you correlate these things" - for me, e.g., oura ring and trackers with health, performance related things. In particular I've been thinking about learning from Apple Music, creating playlists, how it helped me learn about movie I'd never heard about.
  - ... makes me wonder, are there "playlists" for how people have used data from one place, linked to another purpose or source -- learning from what others have done, solutions they cobbled together
- Mad: Regarding wiki, I'm curious about whether there are any specific topics or questions... maybe starting with generic observations. Gary, maybe, mentioned watching what's been happening...?
  - Gary: I think there's an interesting divergence that's happening at this point
    - Personal pages made:
      - <https://wiki.openhumans.org/wiki/User:Dan833>
      - <https://wiki.openhumans.org/wiki/User:Gedankenstuecke>
      - [https://wiki.openhumans.org/wiki/Quantified\\_Diabetes](https://wiki.openhumans.org/wiki/Quantified_Diabetes) (made by Mad for a 3rd pages)
  - Mad: thinking about unified vs split  
<https://docs.google.com/document/d/1DGQ0XaoVWv6KfcatmCYmPFEzaTmF4CCQux2uGBGoJ9Y/edit>

- Gary: reflecting on QS has 900 talks all which have a "user" associated with them -- I've wanted to invite people to update, correct information about themselves
- Mad: it's interesting to note that even Wikipedia's user pages are not "owned" by a user... but by \*custom\* it's managed by the user themselves.
  - Enric: in Wikipedia interactions with others tend to happen in the talk pages, and by custom people generally don't "touch" the user page itself.
  - Bastian: these pages have different "use cases" and that makes me a bit worried about a "unified page". In Wikipedia it's very personal and social glue stuff, e.g. "I love dogs"
    - Mad: well then ... why didn't you make a "public page" for yourself?
    - Dan: I agree with a separate type, where there's more "personal pages"
- Mad: I wanted to note the open question, concept of "notability" that we might wonder about... e.g. what makes it ... reasonable? appropriate? ... to create a page about someone else?
  - Dan S: maybe, if they've published a hypothesis
  - Gary: I think this feels really dissonant with ... how Wikipedia works. I've observed these debates in Wikipedia. I don't think that's a concern, I don't see that as an emerging dynamic.
  - Bastian: Maybe it's not "notability" but ... "appropriate" to be in the wiki? I think it's fair that it's unlikely that people will randomly make pages about "random people"
  - Bastian: I think Mad's other worry is making pages for people that "wouldn't want to be written about in this space"
  - Gary: another problematic thing is people semi-spamming, e.g. creating user, tool page, etc. where someone is proselytizing a particular thing.
  - Enric: if we were creating Seth Roberts' page... it would be very different from Wikipedia's page, I expect, which doesn't have much detail about the experiments he did. I imagine seeing much more details about experiments, protocols, tools. And relevant example of someone that wouldn't be creating the page themselves.
- Gary: we had a criteria for adding "tools" to our database ... because there's infinitely many tools. For us it was ... "has it been explicitly mentioned in a show and tell talk" (linked to a project that used it)
  - Gary: and I'm unsure if it's the person or the project... because projects have fuzzy edges. And I'm starting to lean towards it being the person rather than the project because people have clear edges
    - Mad: I had the same thought, unclear on whether I should be making "project pages"
  - D G: there's public pages that aren't about specific individuals ... these need to be readable enough
    - Mad: I think you're raising a concern about readability of user pages
    - Bastian: may connect to importance of landing pages
  - D G: regarding long lists
- Erik: I think there's two elements maybe - (1) list of tools that have been used / described.... (2) how others have used these tools to do things. My metaphor of playlists would be "a collection of songs" and then "playlist of how songs can be used / combined"
- Katharina: I've written up a summary reviewing what's happening here, won't dive deep into it... [https://docs.google.com/document/d/1olCa\\_H9wPhmVbs6kFQeMQvXZZRpxhKuf5Fhyalmn8W8/edit](https://docs.google.com/document/d/1olCa_H9wPhmVbs6kFQeMQvXZZRpxhKuf5Fhyalmn8W8/edit)
  - I noticed user pages don't show up in "all pages" list
  - would like to put these notes into the wiki... wondering where to put it, how do people know where "open issues" are
  - Mad: the prefix "PersonalScienceWiki:" should be used for stuff like the above - governance, which can include stuff like notes, open issues. (this is called the "project name space".)
    - Katharina: so if I want a page tracking open issues it could go in there?
    - Mad: yes
- Mad: any closing thoughts, needs, on wiki before moving on from wiki discussion?

- Gary: I have a sense of the community side... I can imagine emailing everyone "please go to this URL to edit" but is there anything conceptually to worry about?
- Mad: two issues, one is I/we need to investigate spam reducing barriers eg captchas and I haven't done it yet. the other is, well, we need to figure out how to do the import.
  - Katharina: in addition... I'd really like to see some examples of what these might look like.
  - Bastian: there may be standardized information, and we should be thinking about creating that standardized information in the semantic mediawiki templates before importing all of them
  - Gary: I could do a screengrab of our data entry page where you can see the fields we're potentially using
- Bastian: Apple data export - Richard had found, I played with a bit
  - Works quite well, but not ideal yet -- it doesn't report "where the data comes from". In my case, I have an Oura Ring and Apple Watch, and it puts these all together -- it looks like I have twice as many steps as I really have. (I reported this to the app creator.)
    - Created this: <https://applehealth-dev.herokuapp.com/>
    - Mad: is this like how Overland works? Bastian: it's copy/paste from Overland
    - Overland is an app that logs GPS data but there's no cloud storage, you can give it a cloud server to receive the data.
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# November 2 (Community Call): Self Research Motivations

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: <https://tinyurl.com/376na2bk>

## Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- Enric Senabre Hidalgo
- Dan
- Morgan Hough
- Richard Sprague
- Paula Leonova
- DG
- Soledad

## Agenda:

- Reviewing highlights from interview-based research (Enric Senabre Hidalgo)
  - Related preprint: <https://osf.io/preprints/socarxiv/78yfm/>
  - (Figure 1) Framework for classifying motivations from this manuscript draws on some existing literature in citizen science, personal science, peer production
    - 1. Improving conditions (fix problems) / improve well-being and lifestyle ("optimizer")
      - Typically a starting point to engage for many people we interviewed
    - 2. Enjoyment
      - The act of collecting/working with data, technological tools & doing research in itself as a motivation
    - 3. Extrinsic
      - Motivations beyond yourself, e.g. connected to work/profession, demonstrating skills or potential to use as business opportunity
      - Rarely mentioned as a motivation, but sometimes as an additional motivation going alongside others
    - 4. sharing personal science learning with others
      - in particular, model of [Wolf and De Groot \(2020\)](#)
      - Connection between learning & sharing
    - 5. "shared values" - social interactions, "scientific norms" (Mertonian)
      - potentially the most speculative aspect; to what extent are Merton's norms present
        - Communitas: sharing of findings/outputs present amongst personal scientists
        - "Organized skepticism" was present or maybe more accurately "desired"; skepticism is viewed positively
        - Not so much evidence of universalism & disinterestedness
  - (Figure 2) categories were used to perform coding of interview transcripts; bar chart shows the number of categorizations made for each interviewee
  - Pause for questions:
    - Dan: I'm confused about the fourth category here. Is this referring to group learning?

- Enric: more to individual learning; but we did find learning important in community setting.
  - Dan: what I'm taking from this, the framework is very individual in perspective? I thought left/right on the figure moved from individual to group.
- Dan: it's interesting because I think a lot about the group learning, learn from and share with group
  - Bastian: I think it interrelates; one learns oneself with self research, bringing their own insight and knowledge, and may bring this to a group scale
- Mad: I'd like to explore what findings were particularly interesting, "what's surprising" -- or maybe, how do people doing "personal science" differ in motivations from e.g. traditional institutional scientists?
  - Enric: I think noteworthy that extrinsic motivation was minor
  - Enric: I also think noteworthy that sharing was informal, e.g. via blogposts, rather than via "formal" mechanisms (journal publication)
  - Mad: A counterpoint to this absence of extrinsic motivation is that there **also** isn't a strong presence of the Mertonian norm of "disinterestedness" -- that is, "to benefit humanity, not personally profit" -- that *\*also\** very strong. So it sounds like it's neither a big motivator, nor viewed as "wrong" to do so.
  - Dan: was skepticism tied to a particular "group identity"?
    - Enric: I don't think group identities come up much. There were various terms about the practices -- personal science, everyday science, self researcher. The phrase "citizen science" was *\*not\** very present, which was also interesting.
  - Bastian: one thing that stood out to me was that there wasn't really "one motivation" for individuals. Consistently, individuals had various motivations, multiple motivations - not a single one - which makes it more complex than one might have assumed naively. e.g. Improving a condition, but also -- curiosity, helping a community.
    - Bastian: "shared identity" can often relate to conditions, rallying around this condition, this can be harder or less likely when rallying around some shared interest in e.g. a particular protocol.
  - Mad: I found interesting the evolution of motivations over time -
    - *"Furthermore, we find self-researchers commonly describe expanding or shifting to new self-related focuses over time (i.e. beyond original motivations related to health conditions or well-being), so new topics of motivational focus emerge in an interrelated manner, rather than independently."*
    - That is, people commonly start with an interest in a condition, improving well-being, and new motivations and interests emerge in an interrelated manner from this "starting point"
    - in retrospect this might not be surprising, but might be missed by simplistic explanations (e.g. "why people started" without examining what happens after that)
  - D G: sharing this online debate: : <https://www.kialo.com/everyone-should-health-track---self-quantify-49787> but for tracking only not analysis or making devices etc.
- Richard: my two cents, "what is the point" is important - what do people get out of this?
  - e.g. is there really a belief that people are going to achieve a major, life-changing insight? or is it navel-gazing narcissism?
  - Enric: one observation is the phenomenon "questions lead to new questions" -- these new questions lead to continued interest. I think that's very much a phenomenon.
  - Richard: something whose work I admire is Seth Roberts that's shared actionable insights from his own self research
    - Bastian: regarding "breakthrough findings", these may be rare and asking too much of people to hope or expect this

- Dan: in terms of goals ... I can see "health goals", "tool goals" (e.g. open source), and "science goals" (e.g. findings). I'm curious about how open source interrelates to "science" ethos. Mad: it's interesting to reflect that open source does connect to Mertonian norm of communality (as well as concepts of commons and p2p nature of internet tech)
  - Bastian: the motivations in the model were also drawing on, reflecting motivations in open source communities
- Paula: for my own motivations, I was very interested in understanding how things were affecting me. I bring personal biases, and using the recording and data helps me achieve a more objective perspective on myself.
- Morgan: What about the counterpoint, e.g. Edison just testing and testing stuff until something works.
  - Mad: I guess that's a counterpoint, there isn't a "question" you're trying to answer, but rather "trying to get something to work"
  - Bastian: I wonder if there's a counterpoint, "personal engineering" instead of "personal science" -- you don't care about some abstract question, you're doing things until something works.

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Notes:

- Notes go here
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## October 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: <https://tinyurl.com/2t77jst3>

Agenda topics (order tbd):

- Personal Science Wiki

Attendees:

- Mad Ball\*
- D G\*
- Bastian Greshake Tzovaras\*
- Joyce Waterhouse\*
- dan\*
- Chiara Di Lodovico\*
- Katharina Kloppenborg \*
- Rick Roy\*

- Richard Sprague\*
- Ján Antolík\*
- Gary Wolf \*

#### Agenda topics:

- Mad: Meta-topic of a personal science wiki
  - +1 interest from Richard and D G
- Bastian: I could talk about "what I talk and how" but happy to do that another time
- 

#### Notes:

- Q (D G): can exploratory notebooks be in R?
  - Bastian: yes, and also python with embedded R. Examples below:
    - <https://exploratory.openhumans.org/notebook/84/>
    - <https://exploratory.openhumans.org/notebook/24/>
- Intros during go around...
  - Chiara - first time, doing PhD work on design of wearables for self tracking, so interested in how people are doing this as self researchers. I do personal tracking too using smart watches, muse headband.
  - Katharina - also PhD student on design processes, here to talk about the wiki
  - Jan - new, interested in quantified self and came across slack forums and noticed the meeting
  -
- The Personal Science wiki:
  - The reason for the wiki will soon be a wiki page itself ;)
  - The wiki is currently at <https://wiki.openhumans.org/> (but please don't spread widely yet, as we haven't done anything for spam management etc)
  - Topic pages we started drafting:
    - Gary: [https://wiki.openhumans.org/wiki/HRV\\_\(Heart\\_Rate\\_Variability\)](https://wiki.openhumans.org/wiki/HRV_(Heart_Rate_Variability))
    - Bastian:
      - Meta-topic: [https://wiki.openhumans.org/wiki/Dates\\_and\\_Times](https://wiki.openhumans.org/wiki/Dates_and_Times),
      - Individual project: [https://wiki.openhumans.org/wiki/Sleep\\_recordings:\\_Oura\\_vs\\_Fitbit](https://wiki.openhumans.org/wiki/Sleep_recordings:_Oura_vs_Fitbit)
      - Device: [https://wiki.openhumans.org/wiki/Oura\\_Ring](https://wiki.openhumans.org/wiki/Oura_Ring)
    - Mad: [https://wiki.openhumans.org/wiki/Quantified\\_Diabetes](https://wiki.openhumans.org/wiki/Quantified_Diabetes)
      - and linked stub [https://wiki.openhumans.org/wiki/Blood\\_glucose\\_tracking](https://wiki.openhumans.org/wiki/Blood_glucose_tracking)
  - Richard: are there backups?
    - Mad: there's daily VM backups on DO (in theory), I should look into other ways to backup as well
    - Bastian: TLDR is no we don't plan for the content to "disappear later"
  - Licensing - TODO check and apply
    - Richard: I'm happy with whatever Wikipedia's default is
  - Adding to wiki
    - anyone can add stuff
    - making an account is open, note that this can improve "anonymity" if desired
    -
  - Richard - some thoughts.
    - One of my reservations is that I'm not familiar with wiki formatting.
    - Another thing I wonder about is a way to put in code. For example I'd like to write an article about how to do time series analysis. It'd be since to include sample code.

- Gary: you could link to a github page
  - Bastian: one article I wrote, I wrote to a jupyter notebook
  - Mad: there may also be possibilities for snippets that have monospace format, or templates for code -- in general not extensive code sharing as with github
  - Mad: regarding the first there's a wysiwyg editor that works OK
- Gary - reflecting on the social aspect
  - one thing I think about is e.g. a data export tool (for Apple Health) Richard found out about that I hadn't known about either, and it's the sort of thing I'd imagine learning about here
    - cf <https://twitter.com/sprague/status/1451279714987896851>
- Dan - is there some notification system?
  - Bastian: there's e.g. watchlist to get notifications about updates to pages you're "watching" -- I think this is internal (you see if logged in to the wiki) nothing set up to push this to e.g. email
- D G - can I make a page about myself, what devices I use?
  - Mad: yes, I think that's one of the things this is "supposed" to support, should go ahead and do that if you're interested
    - Mad: an open question is how to navigate "written by self" vs "third person" pages; in wikipedia there's user pages... (should these be unified, or not; if so - what are issues; if not, how.)
  - TODO for Mad: run through the two scenarios on "individual/user pages", pro/con and "how" and "rules" for each.
- Chiara - one issue I wonder about is I've run into accuracy issues with a particular device I'm using, and I wonder if that's the sort of information that would be good to see in a wiki
  - Gary: "accuracy" is one of the major types of questions people have. it's hard though to answer "perfectly" because if/when benchmarking occurs it's specific to a given context and set of assumptions.
    - the challenge in a wiki would be how to connect people to the best "state of the art" on validation or reliability research would be very useful. It reminds me of how Wikipedia has a "consensus" that has a lot of references that can be followed. I can imagine linking to a lot of useful academic work if we can figure out how to frame them.
  - Bastian: I can imagine a section for a tool that says "this tool has been successfully used in [projects and cases] and not for [other projects and cases]", linking internally or externally (e.g. to scientific research).
- Gary - as people make pages, I have a request - include in pages references to any academic/scientific, or user-generated calibration and testing information.
  - Gary - I try to keep a public QS bibliography here - [https://www.zotero.org/groups/2613427/public\\_qs\\_bibliography](https://www.zotero.org/groups/2613427/public_qs_bibliography)



# October 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: <https://tinyurl.com/2t77jst3>

Agenda topics (order tbd):

Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- D G
- Joyce Waterhouse
- Gary Wolf

Topics:

- General go-around - how do go about collecting data? (what, how)
  - Bastian & Gary have stuff, but may be worth postponing to a week when there's more people present.
- During go-around - any additional topics (questions, updates, results) specific to own self research?
  - D G: found burritos are good for me
- General questions/topics:
  - D G: what's up with the wiki?

Notes:

- Link from D G - video I thought was fun, critical of holistic medicine:
  - [https://www.youtube.com/watch?v=wZzEXH5b\\_wk](https://www.youtube.com/watch?v=wZzEXH5b_wk)
- Wiki question
  - Mad: there's something set up and we've planned a small brainstorming session that we're planning; it's just before next week's self research chat
  - D G:
    - the kialo debate would be nice to see as a "wiki page"
    - overview of which device is "best" for a given purpose is something I wish existed
    - general ideas of things I wish were in a wiki:
      - <https://www.kialo.com/everyone-should-health-track---self-quantify-49787>
      - <https://github.com/woop/awesome-quantified-self> is another page
      - <https://github.com/ran88dom99/QS-data-flow-network-graph> alternative to wiki as recommendation for picking dvices
  - Joyce:
    - I have a lot of references from pubmed I think are interesting
    - Mad: I can imagine these are details that aren't topics in themselves, but are the sort of things that would be valuable within a given topic
- D G: TLDR there's a particulr company that's selling burritos and I've been eating them and I feel great - usually frozen food from the grocery store makes me feel sick
  - D G: maybe it's because they're vegan and gluten-free? another brand that's just vegan makes me feel worse
  - Joyce: I'd suggest looking at ingredient lists, try to crossreference and figure out "what" it is

- Dan: if you'd like to make progress, I find it helpful to list a set of hypotheses, maybe ten, and explore them - e.g. if it's the salt, the gluten, the calcium. If you feel sick in a very specific way, may be able to note that. "Feeling better" can be harder, but maybe can track that too.
- Mad: considering the time scale of effect, isolating the effect; I read the tummy trials paper recently (IBS) and the most interesting thing to me was focusing on just the "morning" as the test -- because overnight "fast" followed by a meal, and then subsequent hours noting symptoms -- isolates the effects of one food (rather than trying to disentangle everything during a day, which can get confusing)
- Joyce: time periods can be confusing too. And sometimes avoiding something, then reintroducing, changes the reactivity. Or sometimes "too much" (some threshold below which food is "ok")
- D G: I think the effects tend to be within a day. Isolating with morning, maybe, but maybe need to think about "test" over a whole day.
- Dan: I think it's partly also about what motivates you. Whatever keeps you interested in the process is more important.
  - D G: finding foods that don't make me feel bad, really.
- Gary: I think something came up in the past about hypothesis logging. This seems like a case where this seems valuable.
  - Dan: it feels different from "typical science" because usually you don't want "too many hypotheses". I'm surprised that it seems unusual.
  - Gary: it's rare for people to spend much time recording and reviewing hypotheses
  - Gary: I'm reminded by Alan Neuringer, talk about self research "how many ideas do I have and how good are they?"
- Dan: related to this topic ... how \*are\* people getting anywhere without hypothesis listing??
  - specifically about nutrition... do people not think it's that relevant? or it's straightforward for them?
  - D G: I use very general hypotheses... "this product is good for me" but they're not explicit or recorded
  - Joyce: I think people have hypotheses a lot but they don't call them that. e.g. "does this food make me feel worse". I think there's a lot of folks that think food doesn't affect them at all, or focus on macronutrients.
  - D G: one hypothesis I have is that some foods make me sick in conjunction with exercise, some don't.
  - Dan: I wonder why there's many people that don't seem to worry about food much at all.
    - Joyce: I think some people don't realize the food is affecting them unless or until they radically change their diet.
    - Mad: speaking for myself... the family context of three kids is a lot for me; eating a different set of foods means buying, cooking, and eating separately. That's extra work on top of managing these for the rest of the family. On top of it, I'm concerned about modeling good eating habits for the kids, and this is very hard to do if I'm not eating "the same stuff" as them. Also, I don't have a serious health concern -- I'm sure if I had IBS for example, I'd do it.
    - Gary: I'm always impressed by how much effort food tracking requires. For example this visualization:
      - <https://www.ri.cmu.edu/publications/reflections-on-the-bodytrack-project/>
    - Joyce: there's some interest in food tracking for autoimmune diseases, also long covid, with mymee.com
      - Gary: related, this talk by Dyhrberg (behind mymee) <https://vimeo.com/77197668> ... she's one of the lead people in this area, and has been working hard on how to assist people doing this. e.g. trying an app,

analytics -- personal coaching seems important too. It's just very hard for people.

- Mad: I think there's something really interesting and powerful about "continuous updating knowledge" when requiring some period of commitment to "testing" before learning can make adherence to the "plan" is very hard to do.
- Dan: what about correlation... is there projects that use this and find things?
  - D G: there's exist.io

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# October 14 (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: <https://tinyurl.com/2t77jst3>

Agenda topics (order tbd):

- Go-around discussion of personal data collection processes
- Dan Stutzman & app for data collection
  - Slides:  
[https://docs.google.com/document/d/1p61Zp48JXYxc5tB2q7WR51ZO8\\_TS0s8-LDtvVSC88QA/e/dit#](https://docs.google.com/document/d/1p61Zp48JXYxc5tB2q7WR51ZO8_TS0s8-LDtvVSC88QA/e/dit#)

Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- Dan S
- Joyce
- Enric
- Vytenis
- Richard Sprague
- Gary Wolf
- Dan B
- DG

Topics:

- See agenda topics above

Notes:

- Dan S - sharing an app he's thinking about building, sharing "why" and motivation based on what he's done himself
  - Slides linked above
    - "Ideal" experiment isn't always possible: there's a lot of symptoms, potential metrics, data collection methods, interventions, hypotheses.
    - Reflecting on own experience -- where was a "success" for me? Trying calcium supplements, thinking it might help with mood.
      - spreadsheet supplements with some symptoms - "pounding heart", heart pain episodes, headaches
      - reflecting on it, it seemed like it boiled down to binaries - symptom or not, supplement or not
      - various hypotheses generated over time
    - for me, what worked and didn't?
      - helped: tracking symptoms (provided not too complex to do so), all supplements and food, timestamps not just dates.

- also helped: overlapping/parallel interventions, otherwise it takes too long to explore things
- testing off/on-again micronutrient supplements to see if symptoms return and reduce again
- tracking a daily metric like mood was unhelpful (what type of bad mood?). Working better: irregular, timestamped tags - e.g. "wake", "eat oatmeal".
- Idea: making it easier to log arbitrarily timestamped tags? Imagine to really easily log 100 timestamps tags a day...
  - What would you use it for? What might you log if it were easy?
  - my ideas - foods, supplements, medication, acute symptoms, insomnia / waking
- D G: what correlation algorithm did you use?
  - Dan: just eyeballed it, didn't apply statistics
- Dan B: regarding how people log things, one thing I do is NFC tags that I touch my phone to, to log things.
- Richard: how do you capture non... category tags? e.g. something continuous, like "slept well" vs "didn't sleep well", it's a continuous thing.
  - Dan: I think my sense is that I haven't found attempts at continuous things haven't been useful. When there's a clear "difference" it's been useful. At least, I haven't learned to make it useful.
  - Richard: it's a really interesting thought, I'm not sure how well I learn about things trying to use continuous quantitative metrics, when what I care about is "slept poorly", "slept well".
- Gary: I'm curious how you record the details of diet and supplementation
  - Dan S: an iphone app called mysymptoms
  - Gary: are you also recording amounts?
  - reflection (dan/gary) - generally, don't need to record the amount if it's repeated the same amount every time
  - Gary: btw, there's a tool that existed called Zume that was similar.
  - Gary: I think the way you've tracked things, you've developed the method for how and what tags to use, and that skill is an important aspect of why it's working for you.
    - Dan: it's fair that I'm able to do a lot behind this, e.g. prepare all my own food, a lot went into figuring out how I do it.
- Gary: slide 7 - did you change behavior after this? stopped 3-K?
  - Dan S: yes, stopped. don't have collected data that demonstrates headaches went away
- D G: do you use bitesnap for food? and do you use mysymptoms correlation feature? the "red warning sign"?
  - Dan S: I haven't really used either of those in mysymptoms
  - Dan S: I talk about tags, but it ends up being free text that is later parsed into "tags"
  - D G: I can imagine mysymptoms could be used to do all this, you make a custom menu for what you want to track
  - Dan S: true, but I have a huge number of things I want to track
  - Dan B: does it have voice entry? Dan S: maybe not, might be possible to hook up to Siri.
- Gary - link to the similar app
  - The voice tracking app was called "Zume Life" and when this didn't work, there was a pivot to an app called "Tonic":  
<https://www.mobihealthnews.com/10913/nine-questions-for-tonics-rajiv-mehta>
  - startup that didn't work out. and it had to farm out human transcription, not automated. Switched to a more typical tracking app that was editable.

- Gary - there's something here... there's a bit of a "track everything" mode, slide 7 shows a specific slice, there's so many ways to slice up the world. Wondering how to tame the complexity.
- Mad: there's something interesting about the really low bar for diverse, free form information and converging on what a "tag" or "symptom" is over time and experience -- custom tracking of symptoms is something a lot of people like, there's support -- but knowing in advance what those are going to be is hard. Dan mentioned tags were generated "post hoc" from more messy records. The process of opening up what to record up front, and how that might converge on a custom set... later -- seems interesting to me.
  - Gary: I think the word "post hoc" is important here. The recording process is messy. The organization of the record is happening more after the fact. I see people get caught up in the dream of collecting all the data, but they don't learn -- slide 7 stands out as an example of learning.
  - Dan S: I think I've learned a ton of things related to supplements.
  - Dan S: exploring mouth ulcers, was thinking about vitamin C and scurvy symptoms
  - Gary: you mentioned "I asked myself this question and when I went back" -- what did you go back to?
    - Dan S: I have a journal of hypotheses I keep. And a lot of them are crazy, just not true. Some of them start to look more and more true.
    - Gary: don't worry about things being crazy or wrong. It's normal to find out that things were wrong.
    - Gary: you're doing something that most people don't do here. This is a time series record of everything you think might be true.
  - Gary: so... when you think "did something start after I started taking supplement X?" do you look back at the hypotheses? Dan S: no, I'm looking at the logging for that.
  - Dan B: the idea that you're wrong is awesome. then you've learned something. it's extremely valuable.
- Gary: I've seen tons of projects where people try to track everything they eat. But I don't think I've seen one where they track everything they think might be true.
  - Dan: Without that record of ideas, and how they are used and evolve -- this is just another lifelog.
- Gary: to be fair, things can't easily be "proven" to an external person -- e.g. you have a headache, someone could be an ass and question whether you really have it -- but this process that you use is really interesting
- Dan S: one thing I've found is that many symptoms have so many causes, even a catch-all for different things, they're not as useful to try to track or worry much about
- Enric: I've been interesting in the voice journaling method; I'd been doing journaling for my own project, which was longer entries, facing the complexity of language - synonyms for various things - and how to turn that into data.
  - Dan S: I think one of the most useful things I do is focus on dramatic/distinct changes or symptoms, rather than continuous.
- Bastian: one last question - so you start from fairly unstructured, free text entry, and go back and create more structured data from that. What's the timeframe for doing this? Because the more time that passes, the harder it is to apply structure later.
- Open questions about how well transcriptions would work. Gary: my suggestion is to just give it a try.

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# October 7 (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: <https://tinyurl.com/2t77jst3>

## Attendees:

- Mad Ball\*
- Dan Stutzman\*
- Rick Roy\*
- Joyce Waterhouse\*
- Bastian Greshake Tzovaras\*
- Gary Wolf\*
- Dmdm\*
- Enric\*
- Abhik\*
- Dan B\*

## Topics:

- Mad, Gary - ideas for changing or adding structure around Thursday self research meetings, maybe to make them more motivating or focused
- Dan - two topics I'm interested in, one is the general question of "self research" (how does one narrow the scope of inputs, outputs, when in reality human health is complex and chaotic); other is that I'm very interested in data entry for QS in general, specifically wondering about a mobile app for data entry
- Abhik - not sure if it's a topic, interested in identifying what I'm doing (activity, e.g. "cooking in the kitchen") if anyone's done projects doing that (Dan S - I've got some stuff I've done)
- Rick - been thinking about a simple experiment I might do related to cholesterol ... test, breakfast, test?
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## Notes:

- Rick - I have an egg every day and does that affect my cholesterol? I've been planning to do blood tests with cardiochek, I wonder about doing a before/after test around the morning.
  - Joyce: there's research actually that eggs don't really affect cholesterol levels
  - Rick: that's good to know, I'm not sure what factors might be affected or affecting it. Was wondering what Gary's experience is with blood testers.
  - Mad: you might consider checking high frequency without trying high frequency to see what does vary such that it might be impacted by some intervention
  - Gary: you should look at the paper; it was unusual -- the highest frequency we could find published in humans was every 6 hours. I think it may be because it's been done in mice & based on that it's thought to be pretty well understood, not expected to vary. We did learn there are strong cyclical effects, e.g. time of day is a strong effect (\*independent\* of whether you've eaten; there are circadian cycles), as well as ovulatory cycles -- which is all matching with animal studies, fwiw.
    - <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6484367/>



- Gary: when I've shared this, cardiologists say "sure we've known that for decades" and yet it doesn't seem to impact decisions on when tests are timed for clinical care. It does imply you should "measure the same time every day". On the other hand you'll need more frequent measurements during the day if you want to know "how do meals effect triglycerides". Agree that cost of test strips is a serious limiting factor.
- Abhik: there's this groups that has some cheap lab tests with discounts if you donate your data to reseach :D <https://ownyourlabs.com/>
- Dmdm: lens.org the answer to finding older art like who tested cholesterol
- Mad: I'm very ignorant, what price per strip is it roughly? Gary: I think a couple bucks per. Rick: I was seeing \$45 for a set, 10 lipid panel, 12 glucose (combo package, I think it's the lipid strips that are more expensive). Gary: I think that's high, I think we might've had it cheaper
- Abhik: identifying activities, e.g. cooking, any experiences?
  - Dan - in grad school with a ML class, used accelerometer on my sock. Segmenting mode of transport (bicycling, walking), got very good results with hidden markov models - written up as a class paper, not formally published.
  - Abhik: would love to get that. Also thinking about integrating home assistant platform to use data from a variety of platforms.
  - Dan: fwiw I think accelerometer data is cool, you can do simple stuff with it. maybe not kitchen vs living room though!
  - Dan: what other data are you thinking about? Abhik: I'm thinking about data from air quality sensors... e.g. my presence and use of rooms is reflected, you might notice use of a shower due to humidity, or a door opening due to pressure change.
  - Gary: link to someone you might both be interested in, <http://users.ece.utexas.edu/~ethomaz/>
    - e.g. characterizing activities in a house based on acoustical signals from waterpipes (!)
    - using these environmental and iot sensors to characterize activity, is really interesting!
- Mad - wondering about more structure
  - one idea is to plan a new round of keating memorial talks
  - another is structuring meetings more in other ways:
    - abhik: maybe note in advance if you want to bring/share/ask something, rather than doing it during a go around
    - mad: maybe pick some theme topics for meetings some weeks in advance, so there's more focus on attendance based on interest, planned discussion
  - dan: pre-submit "what to talk about" in google talk, maybe vote on it? or slack?
    - bastian: a bit of a counterpoint, we do prioritize "anyone with slides" gets to go - so we do already prioritize someone with effort. I wouldn't get rid of unstructured meetings completely (less barrier of "need to share ideas formally or don't get to talk")
  - gary: it's useful to be chatting without feeling an obligation driven thing - want the balance, keeping the space without it feel like it's demotivating because we keep meeting and nobody has anything specific to share.
    - I'd suggested a pause until January, and we get together with updates. But maybe that's giving up on something that has value in the meantime.
  - mad: I like the idea of theme discussion topics, inviting Gary to share his (e.g. we might do next week); and Joyce notes that it doesn't need to take a full hour (could be half)
    - Gary: one I'm interested is in how people go about collecting their data, in practice, would be very interested in hearing it
    - Mad: for now I'm going to call that a "theme topic" for next meeting
- Dan: wondering about narrowing scope of inputs and outputs in the context of complexity. What kind of practice to people have for "pre-research" -- gathering metrics, behaviors -- before taking a more structured approach.
  - Gary: have immediate thoughts; I struggle with this myself. Personally I make a mental distinction between "foreground" and "background" data. (There's other ways to characterize,

e.g. passive vs active...) I think of "background" as stuff I was already collecting that contextualizes the data, and "foreground" is something I'm actively wanting to collect to understand it.

- for me, background tends to be: heart rate, location, and activity. occasionally there's some others. these generally exist and I can use to reflect on changes. but these can be hard to maintain; the most useful one (location) in particular is hard to maintain.
- Bastian: do you have example where "passive" doesn't map to "background" or vice versa?
  - Gary: in my recent project I tracked taking my medication... to me that was background data, the foreground was the arrhythmia (the medication was one of various things that might affect it). (And there's ways to make it "passive" but it's not hard to actively track... but I think of it as background.)

And the counterpoint is that my heartrate tracked via fitbit ... which sometimes resets and gets the wrong timestamps... this should be "passive" but then it isn't....

- Abhik: on my end I use a lot of "passive" data, not had to confront data cleaning much... but I note that there's issues where you think the data means X but it turns out to be an artefact
- Mad: something I wonder if is an issue is coming to a "specific question", I'm reminded of Martijn's work with personal science and the importance of coming up with a "good question": <https://www.frontiersin.org/articles/10.3389/fcomp.2020.00021/full>
- Dan: I was wondering if anyone engages in symptom tracking... that's what interests me, not location data
  - Gary: oh, I do collect a ton of symptom data. That's my foreground data, I care about it, I want to understand the causes. The location can help me guess about causes (e.g. seeing a cluster of arrhythmia events at a certain location).
- Joyce: I've been tracking symptoms for 30 years. At one point for example, learned about urinary pH as a potential indicator, and tracking that, which has led to a lot of improvements.
  - I'd use graph paper, charting symptoms, found it kind of hard to interpret, go back and look for patterns.
  - I found it important to write paragraphs that reflect on observations, beyond just specific data items. Daily notes, weekly reflections, sum things up every month. From these, coming up with hypotheses to test over time.
  - Joyce - for me I found that short term changes in resting heart rate were most related / valuable for me to track, understand my symptoms. observing it go up during/after eating a particular food.
- Dan B - around 2010 to 2015, tracked a ton of neurological symptoms I had and everything around my life that might relate to it. I ended because it ended up being solved. But when thinking about passive vs. active -- one thing I do is when I'm noticing a symptom is try to make some predictions in my head in advance. Then, when I get an "unexpected result", I notice that -- building a mental model of what I think will impact.

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# October 5 (Community Call): Quantified Flu paper

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: <https://tinyurl.com/376na2bk>

## Attendees:

- Mad Ball
- Terry Dontje
- Dan B
- Dan Stutzman
- Bastian

## Agenda:

- Chat related to Quantified Flu, in particular related to recent paper (Sep 9 in JMIR):  
<https://www.jmir.org/2021/9/e28116/>

## Notes:

- Invite - any other topics folks might want to talk about
  - Dan B - not much to report, did participate in the UCSF/Oura covid study
  - Bastian - I know I'd be interested to hear about participation in the UCSF/Oura study, since we were partly inspired by it, I didn't participate in it.
- Highlights / takeaways from the paper? (to Bastian, Enric, Mad in particular)
  - Bastian: I'm struck by how consistently people continued to do/use it. The high / extended engagement was one of the results, and something I personally experienced.
    - (Maybe the email format? The visualization? Not wanting to have gaps?)
  - Enric: it was interesting to reflect how the co-creation process took place. We tried to analyze the messages in Slack to understand what topics were discussed, how they evolved.
    - For example each release of a new version/prototype had more communication, responses, continuous feedback loops.
  - Dan S: something that stands out to me most is the continuous development. It also stands out, me wondering how hard it was to integrate all these types of data and wearables, how that happens.
    - Bastian: part of the "luck" was that some of them we already had implemented. So there were only two that were implemented "from scratch"
    - In terms of doing it, continuing to "do it" might have been "how easy it is to do", get an email and click one of two links, one is "nothing to report", the other opens up a brief symptom survey report.
    - Enric: I think it's also interesting how as a collaborative effort, there was less of a pre-defined list of requirements and goals; in contrast more agile/scrum iteration ... in this case, it doesn't seem to fit either model. People would jump in with an idea, an ability to react to that, get it done, try it out.
  - Mad: it stands out to me how the continuous development is at odds with traditional academic research, which has a pre-approval process that makes iteration very hard
- Dan Q: in terms of the paper, how does is this ethics aspect (or lack thereof?) received by academia?
  - Mad: in this case the social science investigation was something that falls under an ethics approval. Bastian: but also we made no claims of ethics review for the analysis.

- Mainly the research here was on the netnography aspects, social science; it wasn't making claims to biomedical research/insight in the publication.
- Dan B: with the oura study they did antibody tests and said we could see the results but then we couldn't, or didn't? But then eventually I did, many months later.
  - Mad: that's probably related to CLIA & regulation preventing you receiving uncertified data that might influence your medical decisions -- the time delay might have made it "safer" to share w/o regulation
- Dan S: wondering if you would publish a medical insight too, not just social science? Mad: well JMIR is medical -- the relevance is how other medical/app folks might consider designing in ways that engage community input, and/or result in a high level of "adherence" (compliance, continued use of a tool/intervention)
- Dan S: why go through the pain of journal publication? Does it improve it? Just for career advancement?
  - Bastian: partly career. partly trying to encourage/show potential new ways to "do research" (we'd like to get researchers to think about how to do more open approaches)
  - Bastian: the Oura study is a contrast - participants didn't have input on design of the study.
  - Enric: these methods, e.g. action research, are becoming more widely used and that's partly due to publication which demonstrates it, brings awareness on how it can be done and potential benefits. Support for funding & cetera relies on publications which demonstrate and legitimize it for e.g. government and academic institutions.
- Dan S: as someone familiar with open source, the publication and academia stuff is a culture gap it's interesting to learn about.
  - Enric: I'm reminded of some European projects that changed approach; did not want to be funding non-open-source projects, increased interest in open source.
  - Mad: I'm reminded of cynicism of funding "new open source" which ends up not being used by anyone else; one answer is to fund existing projects that are used by others - but what else?
- Dan S: it makes me wonder how much funding is necessary to do something like this; certainly a lot of people engage as volunteers ... but then, you pay a lot to get an academic to do anything... how does it interrelate?
  - Bastian: the funding isn't necessary in a lot of ways because so much is because "people want to do it" ... and academics need funding mostly as salaries
    - E.g. jupyter notebooks devs struggle to get any funding; and then google makes collab and has lots of funding for that, but jupyter struggles.
    - In this case ... how much for this? Maybe in terms of FTEs... maybe one FTE for 3-4 months?
    - Enric: the manuscript and such also had a lot of time costs, separate to the "app" itself
  - Notably in academic funding, the timescale is extraordinary - e.g. in France, ask for money, takes a year to get it (and probably you won't)
    - Dan S: makes me wonder who's giving money to whom, where funding comes from. Governments have agencies (e.g. NIH, NSF), you can apply for grants according to a timeline.
  - Enric: I think about crowdfunding approaches too - but the amount of funding here is pretty limited
  - Mad: it's hard to hire someone to do stuff, especially tech/code, easier to find someone that already wants to do it and support it, make it rewarding for them -- so the funding has indirect utility, to create that support or motivation
    - Dan S: the funding was needed for e.g. social science research -- so some there, for other aspects, even if code/tech contributions aren't something you try to pay directly for

- Bastian: reflection that science has also evolved in a direction where it's "team science", needing large teams... less and less a solo effort to accomplish things
- Enric: I'm interested also in democratizing the methods, especially of research
- Dan S: I'm curious about the institutional aspects, in academia ... underlying structure of who's paying for things.
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## September 30 (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: <https://tinyurl.com/2t77jst3>

### Attendees:

- Mad Ball\*
- Dan
- Richard Sprague
- Gary Wolf
- Hongkai He
- Joyce Waterhouse
- Rick Roy
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### Topics:

- Mad: no personal topics, but would like to revisit the wiki idea - invite people to share interest, also to share with folks that might not have been h
- Richard: no personal update, interested in the wiki / resource idea discussion
- Gary: interest in wiki, also some hardware update regarding 1-button
- Hongkai: I'm interested, curious about what kinds of wearables, devices people are using, how open and accessible the data is
- Rick: did my marathon, went well - now want to focus on testing, a cardiochek is on its way to me, planning to use this. have ideas how things might affect the things measured, e.g. during a run.
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### Notes:

- Gary, 1-button hardware update
  - the version of this device that I use hasn't been widely available. Bastian created script to use puck.js but that device has different issues.
  - been talking to Nathan Seidle, may be able to make available as kits on Sparkfun - if interested I'm interested to hear!
  - relates a bit to hongkai's question, because one interest is data access/control issues
- Mad: Discussing the Wiki idea: What is a Wiki?
  - Mad: note that wiki is consensus knowledge - it distills information to a single page, not like a forum thread or discussion. but it's not one person; it's potentially contributed to and maintained by multiple people.
  - Richard: what I'm wondering about is what problem is here and is being solved...
    - if a project can be a template, that you can copy/repeat, and makes it easy?

- another I wonder about is... "what is the community?" there's companies, commercial enterprises that purport to help people get/use this data, or maybe gather it for their own purposes (e.g. 23andMe). there's social media groups.
- Gary: via chat -- These are two links that I used in an earlier meeting today about issues relating to a need for some permanent information resource like a Wiki. The first is a recent post to the QS Reddit, a question about HRV. The second is from a topic on the QS Forum on HRV. The first is low quality. The second is high quality but not easy to get through or mentally process. Could a Wiki page on HRV that included links to expert pages we know about in our community be useful? We could then go in and link to the Wiki page from the Reddit discussion. (For example.)  
[https://www.reddit.com/r/QuantifiedSelf/comments/py6uui/what\\_do\\_you\\_use\\_to\\_measure\\_hrv/](https://www.reddit.com/r/QuantifiedSelf/comments/py6uui/what_do_you_use_to_measure_hrv/) | <https://forum.quantifiedself.com/t/how-does-hrv-work-under-the-hood/9625/16>
- These are examples of a question where I imagine a wiki might contain most of an "answer". I think the reddit responses were not very high quality. In contrast, I think the forum thread is great, but it's not easy to get through. A wiki might be something that stands between these - that distills the information to be more easily understood, and sharable, linked to e.g. on Reddit.
  - It does feel like there's a need for a structured information resource. Whether a wiki would work... is unclear, maybe remains to be seen.
- Richard: the way I think about it, I'd google "HRV" in google, follow links -- maybe find a reddit forum thread. maybe end up in a whatsapp group of hardcore HRVers.
  - Wikipedia seems very successful. But other "wiki" things aren't nearly as successful. Which would make me worried.
  - Another thing I wonder about is notebooks, sharing, including these so others can re-use them.
- Rick: I'm hearing some people may be interested in a topic like HRV, motivated by curiosity and technical interest... others might be interested in a particular problem they have and are trying to solve or improve, e.g. "migraine". Not sure if this is a distinction that should matter.
  - Another thought is wondering if this is a "recruiting tool" for new self researchers
- Mad: it might - or maybe not - end up having that effect, a lot of potential value is just "potential" and might not happen... I want to recognize Richard's point, lots of things do NOT succeed like Wikipedia. It might be important to ask, "why not just get this info on wikipedia". One important issue with WP itself may be its limitation on "no original research" and "notability" that would constrain knowledge sharing with others.
- Dan: have people thought about networked thought tools, e.g. Roam?
- Richard: what is Wikipedia in terms of process, could it even exist or be reproduced.
  - Gary: just saying "wiki" is underspecified. the knowledge is present, but it's tightly held or hard to find, but not on purpose. something I wonder about is what process people share knowledge -- e.g. I might ask Richard, "I'd like you to teach a short course on microbiome" and Richard could do that -- it would be very hand-crafted. is there some way to do that... that's easier, less hand-crafted and one-off.
  - Richard: on microbiome stuff for example, a ton of what I know is basically tools or analysis I had to write myself. so something I really wish we had was consensus on standard data formats and ability to share and re-use analyses.
- Hongkai: I'd reframe it maybe... it's not that the information doesn't exist, and it's not that we don't have access, but newcomers struggle to navigate and find it.
  - In Wikipedia, my impression is that it's like a dictionary, like looking up and reading information for a specific word. But for self research, it's very ... personalized? Searching through this would be very different. Everyone describes things in a different way, has a different focus or attention. Even our language to describe similar activities may be totally different.

- Mad: I think it's a really interesting point about different languages for describing things, and similar to wanting standard formats, I think a lot of this may require converging via interactions, directly or indirectly (via re-using another's code).
- Gary: Hongkai's observation on language and Richard's about standard data feel like different aspects of an underlying pattern.
  - Reflecting on Marco Altini and HRV, one major aspect of his process is creating a standard measurement process about when and how he \*does\* HRV measurements. And I don't think that's very obvious if you browse his blogposts... it's an opinionated insight I think, but I think is needed.
- Richard: one way things sometimes go is that it's not about HRV anymore, but about "my product"...
- Mad: one thing I want to reflect on is how \*individuals\* are represented in a wiki...
  - there are people that do things, and we want to learn about them - their projects, expertise. and to reflect on to what extent individuals are "editing and adding info about themselves or their projects" (as editors) vs. individuals are "experts that are sharing already elsewhere, and might be respectfully and accurately described, linked out to, so others may learn about their work"
  - Richard: it reminds me of "I would never want to be a member of a club that wanted me in it" -- anyone capable of editing to add info about themselves seems likely to do it better, on their own website, make a podcast, etc.
  - Mad: yes... one of the appeals of wiki to me is removing any expectation that an expert is themselves going to add things to it, because honestly I think there are many more appealing ways and places they may want to share their knowledge and activities
- Rick: it seems like doing any of these projects requires a lot of skills ... almost never does someone have all the skills necessary to do a project. If there were a resource where you could draw on others skills.
- Mad: Alan Irwin's "Citizen Science" and the concept of "Science Shops": researchers assist people who come with a specific questions.
  - <https://www.amazon.com/Citizen-Science-Sustainable-Development-Environment/dp/0415130107>
  - Observation: articulation of the problem was itself one of the most fruitful results, biggest challenges for non-experts.

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## September 23 (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: <https://tinyurl.com/2t77jst3>

Attendees:

- Mad Ball\*
- Joyce Waterhouse\*
- Richard Sprague\*
- Rick Roy\*
- Gary Wolf\*
- Hongkai He\*

- Bastian Greshake Tzovaras\*
- Katharina Kloppenborg
- Steven Jonas

#### Topics:

- Brief:
  - Gary - got new 1-button tracker, starting to collect data again but nothing to share and discuss
  - Richard - daughter migraine solution seems to be drink 1 cup coffee every morning, no idea why it works (!)
  - Rick - still collecting data but nothing to share, haven't really started analyzing. marathon this weekend maybe preoccupying me
  - Hongkai - new here, fascinated with how we measure our daily life & decided to join, see what people do. In Boston, work in financial day job, curious about minor physical issues and how one might be more.
- Mad - talking about "resource for tool/knowledge sharing", [related to recent OS forum thread](#) & concurrent thinking/work with Bastian's grad student Katharina
- 

#### Notes:

- Gary - I'm really curious how Richard made that discovery. I know he was exploring all sorts of stuff.
  - Richard - as I previously shared, we'd been exploring all sorts of stuff... diet, ketones... saw a facebook post about salt and potassium, with a protocol that got me thinking...
    - part of the protocol assumed that a migraine is caused when something "overflows". is there something that might cause the "collapse" to happen "regularly"?
    - caffeine is a trigger? instead of avoiding, try drinking coffee every morning?
    - since starting this... only two days of migraine were on days where she didn't drink coffee
  - Gary: what is this concept of "collapse"?
    - Richard: the idea is like a tea kettle... to keep it from "whistling", open it up regularly to let steam out?
    - Richard: migraine as a dramatic reset response where the brain is unable to achieve stasis
  - Joyce: I've heard the parasympathetic nervous system might relate to getting a migraine when this gets activated, wonder if this is related.
  - Gary (via chat): <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4836999/>
  - Richard: another aspect I thought about was "why doesn't anyone else in the family get them" - and a lot of them regularly \*are\* drinking coffee
  - Richard: coming back to self-tracking... I'm not sure how we would have "discovered" this. I can imagine having an enormous spreadsheet and seeking correlation... but finding within all that seems impossible - how would this hypothesis have been found among all the possibilities?
  - Gary: I've seen it's tough to track home potassium, sodium levels - another dimension connected to migraines - people even try using agricultural products for soil sample testing!
  - Mad: to me it demonstrates the power of interventions that deliberately, consistently change an environment, rather than looking for correlations more passively
  - Gary: it can be really difficult to test intervention when there's rare events one is trying to effect; in migraines I've seen trying to notice and measure pre-migraine symptoms, hyperarousal? Thomas when tracking allergy symptoms moved to tracking when his nose itches - maybe there's something "earlier" in the migraine cascade that could be tracked.



- Joyce - heartrate might be something related; e.g. caffeine raises heartrate, causing sympathetic nervous system stimulation, that ultimately reduces potential for migraine
- Richard - maybe. recognizing that I'm an "amateur" in a sense, because I'm not really interested in the "why" as long as the problem solved, whether mountain dew differs from coffee.
- Steven: one thing I find powerful in personal science is that it's easier to re-evaluate theories
- Mad - would like to discuss idea of some resource for sharing resources, tools and projects.
  - Bastian: would like to invite Gary to share reflections, following posts on the QS forum thread. <https://forum.quantifiedself.com/t/would-you-visit-an-internet-resource-that-outlined-every-relevant-and-useful-quantified-self-website/9649/8>
  - Gary: important to be aware of the problem...
    - one is that it's very diffuse, people posting on reddit or quantified self forums, because they're familiar with the theme and idea
    - tools themselves seem not very useful ...
    - maintaining a centralized controlled database didn't work (too hard to update). openly editable approach also seemed to fail - not just spam, but link rot, things turn stale and becomes a mostly-useless collection of out of date information
    - I do think there are a few dozen people that would be interested in looking at it, being involved in some way - but how to use this, make it usable
  - Richard: if you're familiar with the o'reilly series of cookbooks, they follow a similar format. I'm curious if there's a "cookbook" for personal science - list of steps or questions you could do
    - Richard: but then, which tool would it generally use, maybe excel. generally thinking, could it address questions like "I want to do timeseries analysis, how" or "how do I analyze to get statistical significance"
    - Gary: at the other "end" - this idea is very crafted and curated - the other end would be metadata, content. tool, author. revision. searchable, organized. but the problems we've encountered are all with the content.
    - Richard: one of the issues is not knowing you want something until you see it presented, so a highly curated "how to" avoids you not realizing what you don't know
- Mad: sharing one draft idea of a wiki page
  - <https://drive.google.com/drive/u/1/folders/1ySho1Rwl1umyMODgzHTemqS7KE5h7xct>
  - Steven: I wonder if there could be something like Yahoo Questions in a Wiki
  - Gary: it's important to think about what people would use it for - what would a visitor to a page be looking for
  - Rick Roy: I think github is interesting alternative to think about. I like the wiki idea a lot but want to note this alternative
    - Steven: see <https://github.com/woop/awesome-quantified-self>
    - Mad: a difference in git vs wiki is that it distributes the maintenance of the "master" branch; in git a revision has to be accepted by the maintainer
    - Rick: but even if a revision isn't accepted, you can in theory fork it, and people can choose where to go
      - Mad: yes, but this doesn't mean they'll go use that. Conservapedia is a fork of Wikipedia. it fails to centralize knowledge; in fact, people just don't use that version, it goes stale.
- Richard: Alexandra Carmichael Cure Together - something along those lines, I think it was ahead of its time. It's interesting to go back and think about it.
  - Richard: Enter a list of things to try, share data, do things together. It becomes immediately clear to a user what's valuable.

# September 16 (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: <https://tinyurl.com/2t77jst3>

## Attendees:

- Bastian\*
- Mad\*
- DG\*
- Vytenis\*
- Steven\*
- Shelby\*
- Joyce\*
- Sabastian
- Enric\*
- Gary\*
- Vally
- Ismail\*

## Topics:

- Gary - no personal updates, but interesting stuff in forum maybe, debate
- Bastian - no personal updates, but a topic I'm curious about is activity trackers for animals (??)
- Vytenis - curious about glucose monitor devices
- D G - self help books
- Mad: annoyed at things that are nearly impossible to quantify

## Notes:

- Vytenis - there' a few devices for glucose tracking (dexcom, freestyle, )
  - Dexcom has APIs to get data, but doesn't allow
  - Gary: Used freestyle but it's been a few years, but there was a desktop app to export data from, gave you a table. But i think there's some other solutions
  - Bastian: I've used the freestyle somewhat recently. you can read out data directly via NFC onto your phone, and data can be downloaded from a website from the cloud (at least you don't need to install a desktop app).
    - also I think there's some 3rd party hardware for automating reading out more frequently; the provider's software I think only reads every 15m.  
<https://www.ambrosiasys.com/our-products/blucon/>
    - Gary: it sounds like you haven't used it? Bastian: no, just seen it. it looks like it's a little larger than the sensor and you wear it next to the freestyle sensor to send to your phone: <https://www.ambrosiasys.com/our-products/blucon/>
    - Gary: I recall speculation that the 15m interval was deliberate to smooth data, use algorithms to improve accuracy. Bastian: notably you can get readings every 30s if you manually request, this device automates that process.

- Bastian: also I think the freestyle libre 2 sensor has some bluetooth that sends data automatically (?) to trigger notifications or alarms. IIRC they also collaborate with some sports branded version of this same product, costs a lot more.: <https://www.supersapiens.com>
- Bastian - was curious about it when on vacation with dog, tired due to running around, wondered what \*her\* step count was
  - Gary: when accelerometers first came out this was common. for example when schools had fitness challenges, kids would put it on their pet to get the numbers.
  - Steven: I recall a "fitbit for you dog" article a friend sent once, but haven't heard much about projects.
  - Bastian: yes... have seen the products, was curious if anyone has used it
  - Ismail: have seen something trying to predict cat mood
  - Steven: I wonder if breeders and other serious dog people
  - Joyce: I see the fitbark sensor on amazon, hah.
  - Enric: I've also seen pet door sensors
  - Shelby: Heart rate monitors for dogs would have been useful when I was treating mine for heart worms. I had to carry her up and down the stairs to keep heart rate low while she was being treated
- Gary - interesting discussion in the forum, following the HRV lecture from Andrew Ahn
  - Ahn makes a strong case in the lecture that one really needs ekg measures to understand HRV. If you're looking at HRV as a measure of nervous system activation, you need to do it in a way to detect the influence of cardiac nerves on the heartbeat, and that's not possible via optical measures.
  - BUT there's something shared now that seems to claim the opposite - that even just a phone camera can be used.
  - Gary: in my personal use, optical and electrical measures have seemed equivalent but I wasn't looking at HRV, just heart rate.
  - Joyce: I don't use HRV during the daytime, I've thought this metric at night is interesting - tends to get better when my reactions are better. My recollection is that there's a lot of complications on how it's calculated and interpreted.
  - Gary: from what I recall in Ahn's lecture, he goes over different frequencies in variation of HR (including very long, circadian). I think there were two he says can get confused. one frequency related to vagus nerve, affected when you breath in vs out. but then there's another frequency associated with the vascular system, blood pressure, baroreflex.
  - Steven: Marco Altini article about HRV and Apple Watch: [https://medium.com/@altini\\_marco/how-to-make-sense-of-your-apple-watch-heart-rate-variability-hrv-data-89bf4a510438](https://medium.com/@altini_marco/how-to-make-sense-of-your-apple-watch-heart-rate-variability-hrv-data-89bf4a510438)
  - Gary: Ahn reflects on history of HRV, notes that clinicians see it as meaningless.
  - Joyce: I've interacted with Gustaf Kranck, Vagus app, and he's also expressed an opinion that HRV is useless.
  - Gary: one thing I felt I learned from Ahn's lecture is that arrhythmias are extremely common, and they like to filter out all arrhythmias and only look at the interval between \*normal\* heartbeats. So... the optical measure can't do this, can't discard abnormal heartbeats (arrhythmia). I think Marco's counterpoint is to claim that it's possible to get around this (how it's calculated, or controlling conditions for measurement).
  - Mad: maybe they're both right, if someone doesn't have arrhythmia it "works" much better. Gary: well Ahn states that they're \*really\* common... but I think Marco's article might imply there are routines and behaviors that could be controlling this.
- D G - curious about self help books. I found "atomic habits" to be really good. also "13 things mentally strong people don't do"
  - Joyce: "the pulse test" is old and a large influence for me.
  - Ismail: if it's habits, I loved Dopamine Nation

- Steven: if it's about behavior, the CBT workbook for depression, and for anxiety, are interesting to me. Notably there's evidence that a patient using the book is as effective as therapy. Another one that comes to mind is Seth Robert's Shangri La Diet, where he details a lot of self experimentation that led to a diet theory that was very different from standard theory, and then diving into literature -- I think more about reading about his process of self experimentation, rather than the conclusion.
  - Cognitive Behavioral Workbook for Depression: <https://www.powells.com/book/cognitive-behavioral-workbook-for-depression-2nd-edition-a-step-by-step-program-9781608823802>
  - Shangri La Diet: <https://www.powells.com/book/shangri-la-diet-9780399153648>
- Mad: I've found my DBT worksheets book really valuable. Also was interesting to get the therapist's own manual and see the goals of therapy, less ... charitable descriptions of patients' issues.
  - And I learned that these DBT things created by Marsha Linehan may have a personal "what worked for me" pragmatism - she's stated that she believes she had BPD, see: [https://en.wikipedia.org/wiki/Marsha\\_M.\\_Linehan](https://en.wikipedia.org/wiki/Marsha_M._Linehan)
- Shelby: Jordan Peterson's books are highly philosophical but I enjoy them [https://en.wikipedia.org/wiki/12\\_Rules\\_for\\_Life](https://en.wikipedia.org/wiki/12_Rules_for_Life)
  - Vally: Second Jordan Peterson as well. 12 Rules for Life was a good book
  - Shelby: Jordan Peterson's are audiobooks, you'll feel like he's yelling at you the whole time but it's inspiring. With a Kermit the Frog-esque heavily Canadian voice.
- Shangri La Diet: <https://www.powells.com/book/shangri-la-diet-9780399153648>

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# September 9 (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: <https://tinyurl.com/2t77jst3>

## Attendees:

- Bastian\*
- Rick\*
- Steven Jonas\*
- Dan\*
- Joyce\*
- Kate\*
- Gary\*
- DG\*

## Topics:

- Steven: Potential topic: tracking of babies (eating, feeding, sleeping, self-tracking for maintenance)
- Dan: Emotional resilience, any metrics others have tried and found useful?
- Rick: creating a baseline of blood lipids
- Gary: Organized a forum talk on heart rate, an interesting discussion of this protean measure.

## Notes:

- Steven: I found in some projects that even high burden of tracking is okay if it gives real-time usable feedback.
  - Bastian: Weight would be an example, you track it regularly and look just at the last few data points to see a trend normally
  - Kate: Reminds me of using the Oura Ring and trying to maximize HRV
  - Steven: Workouts are an example too, former performance gives feedback on when to workout more/less
  - Bastian: not everything might have an immediate effect, so realtime feedback might be less valuable or useful
- Dan: working on improving emotional resilience, but having a hard time finding any metrics that might be good to keep track of
  - Kate: How would you define it? Do you want a single scale? A couple of questions?
  - Dan: Not even sure of that
  - Steven: defining what is the exact well-being that you want to track? I think it's important to find that out first, to make sure that one looks at the right thing. 3 approaches come to mind
    - One-button tracker: leads to having to answer what the thresholds are for pressing, what are triggers, the process itself might be valuable
    - case/crossover design: when you have a really good/bad emotional resilience experience, take note of what you did in the past, to find common factors
    - Nightly ritual of reflection over the past day
- Gary: There's a really good conversation on heart rate going on in the QS forum:  
<https://forum.quantifiedself.com/t/how-to/9636/10>

- One participant, who has been bedridden for a while has been using minute-by-minute HR data to calibrate exertion levels, seems like a well-known practice in the ME/CFS community, c.f. <https://www.physiosforme.com/heart-rate-monitoring>
- Have a list of emerging 'best practices'
- Steven: reminds me of a talk at 2015 QS conference.

# September 7 (Community Call): AutSPACES

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: <https://tinyurl.com/376na2bk>

Attendees:

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Agenda:

- **About AutSPACES**
  - The AutSPACES project is a unique citizen science project using participatory methods to gain a better understanding of the experiences autistic people have navigating public environments.
  - To do this, we are developing a platform to collect real life stories from autistic people, and using Open Humans to store all our data.
  - We want to use this community call session to introduce to you our project and our practices, and take the opportunity to get your views on some of the issues and challenges we are facing.
- Links etc:
  - <https://github.com/alan-turing-institute/AutSPACES>

Notes:

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# September 2 (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: <https://tinyurl.com/2t77jst3>

## Attendees:

- Mad\*
- Abhik\*
- Rick Roy\*
- Joyce Waterhouse\*
- Dan\*
- Enric\*
- (Ismail Elouafiq - joined later)
- 

## Topics:

- Abhik - nothing in particular, thinking about incorporating heartrate ... or EEG pipeline work ... trying to decide, might be nice to brainstorm
- Enric - nothing about myself but a friend asked about breathing through "nose" vs "mouth" and I was curious about what she might ask/wonder with that
- Joyce - nothing to talk about, but could update on additional observations (and have thoughts about breathing)
- Rick - no progress in my own stuff, but thinking about for QSers how people interact with their healthcare professionals ... gap here, why it exists
- 

## Notes:

- Enric ("asking for a friend") - posts a friend shared about humans "used to breath through nose" much more
  - ... came from someone also recommend things like "cold showers"
  - Mad: this reminds me of "paleo" arguments (was this really the pattern historically? and is it necessarily "worse" to be different in modern context? it sounds like there's a chain of claims and potential assumptions and I think skepticism always important)
  - Mad: what were the reported benefits?
    - Enric: if I remember correctly, it had to do with sleep quality, and something related to heart
  - Dan: I think this may come from a book "Breath" by James Nestor that I've been reading, only partway through -- I think another claim was dental issues were related to a cultural difference in breathing
  - Joyce: someone before Nestor that wrote about this was Patrick McKeown
  - Enric: something of interest to me is whether she can use the fitbit to observe changes -- maybe because there's no change at all -- but maybe it's not the "right tool" to detect the relevant change
  - Mad: my gut feeling is that a tracker is likely to be unsatisfying; I'd be wary of recommending it if someone isn't \*already\* using it. An alternative is journaling ... maybe something Steven



Jonas has suggested: writing down hypotheses prior to starting, "what you think will happen" and then revisit this while/after doing the thing

- Rick: I'd observe that an observed change might be due to a change of season -- rather than being due to breathing through the nose. Notably a lot of animals that can only breath through nose; humans use breathing through the mouth for example to get more air while running (despite disadvantage of "not filtering"). It might be really hard to sort out "fewer problems" vs. environmental changes due to season. Also... mouth breathing can dry it out, another effect.
- Abhik: drying out might be another way these affect the body, and also maybe a way to detect "compliance". Regarding "filtering", I wonder if air sensors would be interesting contextual data (how much is in the air that's being breathed). If with Kate were here, maybe she'd know more about how to use the fitbit, maybe HRV...
  - capacitor soil sensors might be useful for checking moistness, extent to which "drying out" occurs
- Dan: one thing I thought was interesting was the nose acting as a "humidifier" preventing the lungs from getting as dry
- Mad: there's a known effect on sleep apnea and snoring regarding keeping jaw closed in a certain position and nose breathing. That alone could have an impact on sleep for many people.
- Abhik: EEG thoughts
  - I wasn't too familiar with classifiers ... getting raw sensor data, building a classifier to determine sleep stages vs. awake. (Maybe some daytime states too.) But I've never build a signal processing system like this before.
  - Mad: are you thinking of using machine learning? I'm curious about how you create the training data
  - Abhik: not sure, maybe use the high confidence classifications from an activity tracker ... maybe there's a rule about "certain number of delta waves"..
    - Mad: I think using the activity tracker would end up with a circular issue if you want to ask "are activity trackers accurately determining sleep stage"
    - Abhik: there's some open data sets that have been classified and classifiers available online. Labeled by professionals. But the locations of the sensors from these data sets are different to my device.
    - Abhik: I still need to do some exploratory data analysis
  - Mad: what about just figuring the "metrics" that are used to define sleep stages -- can you count or measure these? forget the "stage" construct, most of these are a bit arbitrary other than "REM" which is really obvious eye movements
    - Abhik: I agree that I'm skeptical of how meaningful the stages are... when what I really care about is how good I feel.
    - Mad: very true, and this question might not be relevant -- just curiosity -- REM \*is\* very distinct
    - Abhik: it can be really hard from EEG sensors alone and not eye movement detection -- it looks a lot like being awake again on the other electrodes. stage 1 is like "drowsy", goes more and more "deep", then REM like "awake again". I think... eye movement is picked up.
  - Mad: a reason I asked about whether you can extract the "stage-relevant" metrics themselves (period of waves, spindles, eye movements) rather than using data "classified on stage" was... wondering whether clusters of "types of sleep" show up, without informing the model that certain types of stages are expected.
  - Enric: wondering about what the existing practices are
    - Abhik: there's some standardization on data format on "electrode placement", methods to clean data, but there's a lot of hardware/software specific combination

(certain data processing is specific to the hardware). There's not much literature and work out there on EEG data collected outside highly controlled environments -- calm and sitting, or asleep -- I think those are really interesting, "what are brains doing during the day" (!)

- Mad: that sounds different from sleep, maybe you shouldn't be so focused on that...
  - Abhik: I think there's a human tendency to want to measure things that are easier to measure -- and sleep ends up being more tractable :)
- Joyce - EEG observations
  - noticed delta waves clearly in response to hot flashes, and also in response to food triggers
  - trying to control for other potential factors e.g. effect of chewing on signals
  - Abhik - In my experience, my sense is I think signals are probably generally good during general use during daily activity. but wanted to share a story about noise in the data in my personal experience: strong peak at 59 or 58 Hz in the signal, that disappeared when I pressed with my hands. thought this was a contact issue
    - but then realized it disappeared when I just shielded with hands (no contact!), and can also make it disappear with foil. don't know what is causing it (tv? some other electrical thing?), but it's very specific so easy to filter out.

## August 26 (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: <https://tinyurl.com/2t77jst3>

### Attendees:

- Mad\*
- Joyce\*
- Gary\*
- Enric\*
- Dan\*
- D G\*
- Rick Roy
- Bastian\*
- Derrick Roberts
- Steven Jonas

### Topics:

- Joyce - not really, could update on current project, maybe unrelated question related to work
- Gary: replaced one-button and had some discussion about it, could talk about one button stuff ; also took a lot of notes about HRV from an interesting talk
  - Rick: reading forum; was thinking about one button... wondering about using click patterns to indicate certain items (e.g. short/long/short)
- Steven: recently started a job, already seeing a lot of things changing in terms of stress and tracking behaviour but nothing to share yet

### Notes:

- Derrick - intro, work with data a lot, visualizing it & into using sensors (arduino, raspberry pi), e.g. using detector to track indoor temp to observe AC use & realizing how much one could see in the data about what was going on inside
- Gary / one-button tracker:
  - wrote up in forum - <https://forum.quantifiedself.com/t/one-button-tracker/9618/4>
  - in theory: press button and get a timestamp. No clear/best commercial instrument for doing this. Custom device by Thomas & Jakob isn't purchaseable. Puck.js has some (different?) downsides, e.g. false positives. (also Gary ordered & it was held up in customs for 6 weeks...)
  - Enric: reflecting on the psychological effect of "awareness of pressing the button", increasing awareness of the phenomenon. For me it almost felt like... "I'm going to press the button, and then 'experience' what I'm trying to study" -- almost an opposite effect? the button prompts awareness, not the awareness prompting the button.
  - Gary: the meditation tracking was tracking return of attention (noticing I wasn't meditating). I had a hard time analyzing the data... it was very dense? scattered, clumps...? never developed an analytical approach to it.
    - BUT the act of pressing it changed my experience a lot, increasing my awareness -- to the point I was using a button that I knew was broken (!) because it made such a difference for the experience/practice of meditation.
  - Steven: the haptic feedback (in Thomas & Jakob's button) seems important too. Another thing I notice is that you need to create the "filter" -- the definition for what triggers a button press -- training your brain to have increased awareness and understanding of the phenomenon. The positive consequences of this might be an important factor in people wanting to continue active tracking.
  - Enric: e.g. tracking smoking to try to change a habit
  - D G: in atomic habits this is called "point and call" technique for bringing awareness for habit change
  - Mad: I wonder if there's an added aspect of "accountability" -- not merely that you're increasing awareness, but for anything that you want to reduce or avoid (innocuous or not) is something you feel accountable because you're logging it happening.
  - Steven: also importantly, having "bandwidth" to actually engage in active tracking -- when under a lot of stress -- to be realistic about what's possible, actually starting an active tracking habit is hard
  - Enric: figuring out the protocol for me was an issue, needing to simplify what I'm tracking (e.g. one single thing) because you can't just add more buttons
  - Gary: it reminds me of more general issues of designing protocol, which data to use and get... I think of some types as "foreground" data, especially for active tracking; but then add context via passive/background data (e.g. "where was I when this happened")
    - one mistake is lacking background, lacking context to understand "foreground"; a counterpoint is a ton of background data and not knowing what you want to use it for
    - D G: if I want to test what affects typing speed, I can just track it and compare it to everything else; Gary: we see a lot the complexity of what might affect cognition, and there's so many things, generally you need to have some sort of hypothesis that's more specific ...
      - Steven: reflecting on a case where someone that optimized sleep (in order to feel better) and ended up missing a social experience (morning workouts with friends) ... which he later reflected may have had an opposite effect (didn't feel better to miss those!)
  - Bastian: to Enric, how much did you actually make use of the button presses in analysis? or was it more the notes? did the button presses help get you to write notes?

- Enric: I feel like the annotations themselves wouldn't have given me as much insight into the visualization of that information over time; Bastian: but the notes had timestamp so in theory you could graph only those ...
- Enric: that could be done, but I would feel like I wouldn't have as much insight. Also the "intensity" estimated via button press length was informative (graphed as size of bubble) and I think that would be much more difficult to infer from notes alone.
- Gary: I've noticed a "trust" factor in using the button vs. using a note. I don't know whether that's \*reasonable\* ... the one-button data does match daily notes about "bad day" or "good day", and I feel like the one button data is more reliable.
- Joyce: my own experience with doing extensive note-taking... I'd come up with lots of ideas about "what was going on", but being able to "measure" more objectively made it possible to do hypothesis testing.
- Mad: I've been wondering about what makes a good use case for the 1-button, and what doesn't?
  - Steven: I think one thing that trips people up is when the thing they're tracking has some sort of "dimension"... e.g. "when I feel happy"
    - Mad: and that dimension is internal? (not like: I sneezed at least twice) so you have mental load trying to decide if it's met a threshold.
    - Bastian: in addition, "why did I press the button" in Enric's presses, positive or negative was missing in the press itself
  - Gary: identifying a "trigger" is a key part of the protocol. I've found two things that work for me... one is an intrusive phenomenon, like a sneeze -- for me, hunger, or arrhythmia -- these are hard to ignore, they intrude on my awareness. The other is a routine trigger, e.g. "when I take my medication" or "when I go to bed".
    - ... but what's harder is something that's NOT intrusive, trying to be aware of a phenomenon such that you'll hit the button.
- Gary: tangentially related to "when do you do the measurement" I'm reminded of this forum post...  
<https://forum.quantifiedself.com/t/using-heart-rate-data-to-detect-food-intolerances/9505/8>
- 
- Gary / HRV - watched lecture about HRV  
<https://www.physioq.org/lesson/hrv-antiquated-or-indispensable-part-1>
  - Gary: highly recommend this, lots of knowledge about HRV, including historical/medical context of where it was used in the past -- and how it's of interest, especially outside clinic vs. lack of modern clinical interest in the metric
  - the historic interest from various fields, from obstetrics to neurology
  - gets into fourier analysis of HRV and timescale is associated with different physiological aspects, from breathing to hormonal
  - and then, "how do you use HRV without having regular heartrate?" for me this was very interesting because I (with arrhythmia) experience this myself! and it has lots of knowledge on how to do this.
  - Part 2 will be Sep 13.
  - Gary: one favorite detail was showing publish research about how using a needle to stimulate vagus nerve affected breathing and HRV -- and he reflects, "how did they find participants to consent?" wondering if it was self research by the researchers, because the procedure is so risky (!) -- and I checked the paper, there's no clear evidence on who participants were, but maybe!
  - Steven: reminded of book "Self Experimenters" --  
<https://www.amazon.com/Self-Experimenters-Sources-Bibliographies-Indexes-Medical/dp/0313323488>
- Joyce - with my own EEG stuff, some interesting observations

- delta waves seem to clearly go up with hot flashes, and also seem to go up in response to food triggers
- some reading indicates that delta waves seem to be associated with symptoms ME/CFS; also intrusion of "waking" state into the night... hypothesis that a lot of activation at night that makes sleep is "unrefreshing"

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## August 19 (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: <https://tinyurl.com/2t77jst3>

### Attendees:

- Bastian\*
- Gary\*
- Joyce\*
- Francie\*
- Kate\*
- Steven\*
- (Will)
- Dan\*
- Abhik\*
- Ricky

### Topics:

- Gary: Have some things on projects i'm working on
- Dan: 1-2 questions if we have time
- 

### Notes:

- Gary:
  - Inspired by Enric's talk:
    - One of the things mentioned in the talk was the puck.js as a one-button tracker and he found a lot of false-positive entries. The one-button tracker from tottilabs has a really good design to avoid false-positive presses, but it's hard to get them right now. Talked to Thomas & Jakob about this, they are also frustrated about lack of availability and have experience in 3D printing, thinking about making custom casing for the puck.js.
    - Abhik: Maybe also local makerspaces could help printing the things from a file if it was shared. I used just some paper in my puck.js casing to tweak the resistance of the pressing
    - Bastian: There's two things: 1. Is the false-positives, which could maybe be solved by implementing a 'double-click' to avoid those. But then there's also the issue of the button breaking off because of the weird positioning

- Working on a cohort-based course on personal science together with Steven and others
  - Potential way forward for QS & Art27. Thinking about using one-buttons as reference tool. Goal would be a paid course, not targeted for traditional students
- Student in QS forum working on learning self-observation, lead to being interested again in the tremor tracking. Biggest problem in the past was trying to collect data through phone app that makes use of gyroscope/accelerometer
  - Abhik: When do you notice the tremors?
    - G: It's in fine motor movements

# Keating Memorial Show&Tell Talks

## Details

- Date: August 12, 2021
- Time: 10:00 Pacific/ 13:00 Eastern ((US and Canada), 19:00 CDT Time
- Join the meeting here: [Meeting link](#)
- Passcode: 519184

Presenters (add your name here if you may have a presentation, and Gary will be in touch)

- Enric Senabre

## Announcement (post anywhere)

**You're invited to attend the 2nd Annual Steven Keating Memorial Self-Research Talks.**

**This ninety minute online meeting will present 4 first person self-research talks with discussion and Q&A.**

**Time: August 12, 2021, 10:00 am Pacific Time (US and Canada)/19:00 CDT (Europe)**

**You must RSVP to be admitted to the meeting. Please use this link:**

<https://forms.gle/QjWmh5kQqnazzJL77>

**This meeting will take place online in Zoom. We'll have our regular show&tell format where people share what they learned from their self-tracking projects. Presentations will be in English.**

**Where do our talks come from? They come from you! Do you have a personal self-tracking story to share? Please let us know by filling out the form here when you RSVP.**

**This event is being cross-posted with other Quantified Self meetups.**

***To learn more about Steven Keating, watch his talk: "Can Selfies Save You?"***

***<https://www.youtube.com/watch?v=U5SafKJgqPM>. To learn more about why these self-research talks were undertaken in his memory, please read this blog post by Mad Price Ball:***

***<https://blog.openhumans.org/2020/01/30/keating-memorial-self-research/>.***

# August 5 (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: <https://tinyurl.com/2t77jst3>

## Attendees:

- Mad Ball\*
- Bastian\*
- Joyce Waterhouse
- Gary Wolf\*
- Dan B\*
- Shelbey\*
- Rick Roy\*
- Enric\*
- Abhik\*

## Topics:

- Show & Tells next week
- Dan: question time spent on building/maintaining infrastructure vs. analyzing data
- Rick: (1) have a backburner project, thinking about getting data together (related to running) and a model for it (2) professionally working on a startup med device re blood biomarkers, if that's of interest
- Abhik: collected data & would be interested in feedback on stuff so far, interested in giving a talk if but have procrastinated so not sure if it's ready or appropriate

## Notes:

- Q&S talks:
  - Having a practice talk w/ Gary or Steven is strongly encouraged/preferred to get feedback & adjust. For scheduling, reach out to Gary (via Slack or email)
  - Gary: At least three talks I'm pretty sure about:
    - Enric, Joyce, Gary
    - there's also some that responded to meetup, both people that haven't been very involved in the self research chats; they're both aggregation/platform type talks more than personal projects -- inclined to focus on the "personal question" aspect over "technical challenge"
  - 
  -
- Abhik:
  - Now up to 6 sleep trackers, all of which disagree, idea was to compare results
    - notably including EEG (Muse), Apple Watch w/ AutoSleep, Amazon Halo, Oura Ring, Fitbit Charge 4 & Withings in-bed sensor
  - Gary: in terms of a talk, I think if you wanted to show results from multiple sleep trackers would be very interesting
  - Mad: I'm not sure what you mean by not being able to do analysis; if you can graph them on the same graph that alone is interesting (but I don't know if you're able to do that)
    - Abhik: I'm nervous about being able to do that. Bastian: I'd be happy to help, graphing stuff is something I've got a fair amount of experience in
  - Abhik: thinking about how to incorporate Muse, whether to use raw vs. their sleep app



- (worried that raw is better because sleep app might not get naps)
- Gary: would you be ready to share a practice/prelim talk on Tuesday?
  - Abhik: sounds good
- Aside re last week & slack, data export unreliability
  - <https://www.beiwe.org/exporting-the-same-data-from-a-wearable-twice-doesnt-give-you-the-same-data/>
  - Shelby - re beiwe, some colleagues have proposed digital phenotyping research using it :)
- Rick: heartrate data collected while running
  - been using heartrate strap that came with a Garmin device in 2011, and have used when I run, when running, it seemed that my heartrate didn't vary a lot
    - since then, been told that small differences can be significant, so maybe worth examining more closely
    - also GPS data from the Garmin 405 watch tracking running path
    - notes from runs on how I was feeling?
    - can extract weather info, e.g. whether it was a hot day
  - also curious about maximum heartrate declining with age, and whether that's been true for me as an individual
    - since there's so many influences, level of fitness etc
    - and ... not sure that when I'm running I'm actually pushing and achieving \*maximum\* heartrate? maybe it could go even higher?
    - how does weather affect things?
    - do things like incline have effects, how do they affect things? (e.g. lag after going uphill for a while?)
  - been collecting a lot of data in the last couple years especially, and running the same route
  - thinking about stuff like ... PCA to ask which components really matter?
  - Shelby ... I've noticed that food and alcohol can be major influences in my experience on heartrate, especially during exercise
  - Mad: I'm curious whether you've exported data, confirmed it has information you want in it -- how far you've gotten in this process
    - Rick: I'd like to start by using the GPS data to determine areas that were uphill, downhill, flat -- a couple routes that have these consistently
  - Gary: this sounds really interesting, but I'm wondering if you can rephrase the question, what you're trying to get at
    - Rick: I'd like to end up with a mathematical model for my data that says: "my heartrate is predicted by the following equation, using variables (speed) (uphill/downhill stuff) (maybe additional factors e.g. age, weather)
    - Gary: are you hoping this helps with training, or otherwise hope to use it for or learn?
    - Rick: I'd like to learn how much these things matter regarding my heartrate. Or don't? Are they such minor effects that they're lost in the noise. e.g. to what extent does my age actually matter.
      - Not really to improve my performance... but more to know how much different things matter
  - Gary: I think if you're trying to develop a model that predicts across a large range of conditions, that sounds really difficult.
  - Rick: also worth keeping in mind Shelby's point that some unrecorded factors may have noise that isn't captured anywhere here
  - Dan: I did something somewhat similar, with a specific incident (hiking data from Garmin, did hiking a lot in one year) -- ran into a bear at a couple points
    - constrained to whatever Garmin provided for data access... limitations due to binning
    - used this to build a predictive model -- was able to get something that seemed to work. specifically... "seeing a bear" seemed to increase HR by 30bpm

- something to think about is if you can see outliers in data, how they might be explained
- Rick: one thing I recall was some dogs coming out and chasing me; I stopped, guarded... later wondered to myself "I wonder if it would have fallen faster without that stress".
  - Have been collecting post-run HR falling post-run as I cool down by walking
- Mad: Your data set is really unique in that you have this long-term data, there might be interesting signals in there for how the influence of variables changes over time
  - Rick: also I think there may be an annual pattern of training, because I'm getting less training and running during the winter due to the snow
  - Bastian: I think since you have multiple years, that positions you well to disentangle these -- what's due to training, vs aging, etc
  - Rick: I think the data has been collected much more consistently in the past couple years, since 2018

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# August 3 (Community Call)

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: <https://tinyurl.com/376na2bk>

## Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- D G
- Scott Williams
- Andrew Ahn

## Notes:

- Go here
- Potential topics for next community calls - Tue Sep 7
  - Bastian: AutSpaces project has had some interest in sharing progress, where they are, maybe invite people to get involved
    - Current status: active contributing community (for development; not soliciting) no longer active funding from Autistica nor working with Fujitsu
    - Bastian will check with them whether September meeting would work for them
  - Self-research chats: Changes to organization/structure? Are we happy with the current state or do we think there's potential improvements?
  - Notebook set-up and what could be improved there
  - "What is Open Humans / where is it now / where is it going"
- Andrew Ahn
  - Sharing work with PhysioQ, enabling students and communities to create projects around their data
  - Bastian: maybe of interest is neurotechx
  - Mad: maybe of interest is Vineet Pandey, interested in citizen-led/initiated - past work with Galileo (<https://dl.acm.org/doi/abs/10.1145/3411764.3445668>)
- Self research presentations
  - Aug 12 - self research Quantified Self Show & Tell (see info [above](#))
- Also we have a slack at [openhumans.slack.com](https://openhumans.slack.com) -- get an account using: [slackin.openhumans.org](https://slackin.openhumans.org)

# July 29 (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: <https://tinyurl.com/2t77jst3>

## Attendees:

- Mad Ball\*
- Bastian\*
- Rick Roy\*
- Richard Sprague\*
- Dan B\*
- Ivet Avalos
- Joyce Waterhouse\*
- Enric Senabre\*
- D G
- 

## Topics:

- Plan for QS show & tell on August 12 ([see details above](#))
- Richard: could have some questions about R debugging
- Enric: Update on additional data source -> ActivityWatch
- Joyce: General Q

## Notes:

- Keating Memorial talk Show & Tells
  - Registration for it at <https://forms.gle/QjWmh5kQqnazzJL77>
- Joyce - I was thinking about this statement for my talk... related to Arthur Coca (immunologist) and work on food reactions, calling him the "the grandfather? of quantified self and personalized medicine"
  - Bastian: I think Gary would likely point to Santorio as a historic example <http://www.markwk.com/2017/06/history-of-weighing-scales.html>
  - Enric (Mad concur): also think about Seth Roberts [https://en.wikipedia.org/wiki/Seth\\_Roberts](https://en.wikipedia.org/wiki/Seth_Roberts)
    - Enric: also maybe of interest: Weisse, A. B. (2012) 'Self-Experimentation and Its Role in Medical Research', Texas Heart Institute Journal, 39(1), pp. 51-54.
    - <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3298919/>
    - Enric: I've also noticed if you look at Wikipedia articles about "self experimentation" there's different lists depending on language ;) (English vs Spanish vs German). This is unusual in my experience, Wikipedia pages usually just replicate across languages.
- Enric - wondering about if/how to use ActivityWatch with the research I've been doing with "not using my smartphone" (using a dumbphone + laptop whenever possible)
  - ... and last three weeks I've been using the smartphone, and curious about this change, if there's anything that's changed
  - Done so far: graph of timestamp data using one-button -- these record reactions I'm feeling/experiencing to "not having the smartphone", plus text notes I took about what it was and what I was thinking
  - What I'd like to do: do something about what's happened since I've returned to using the smartphone

- Using ActivityWatch... I guess similar to RescueTime?
- But, don't have data from before the intervention
- Bastian: what do you hope you might learn from the data?
  - Enric: I feel like there's changes in my behavior since before the intervention, but it's just an impression.
- Mad: I guess it's limiting since you don't have ActivityWatch from before intervention... but I recall you took notes/observations about what you "missed" or "wished you could use the phone for" ... it might be interesting to see if you can use the data to explore "what do you wish you were using the phone for" vs "what do you actually use the phone for"
- Bastian: agree that it'd be hard to do much otherwise without more data, e.g. needing to combine data across laptop and phone e.g. for whatsapp
- D G: when I've used ActivityWatch the database for the app can get too big after maybe six months; it needs to be moved so a new one can be started otherwise the app will get slow
- Bastian: it looks like ActivityWatch on a laptop -- I recommend using that same tool so it's easier to combine data over RescueTime, if you do decide to add something to track laptop use
- Dan: tangential question I've had, when I've tried to look at time logging I haven't really been able to combine iPhone tracking with anything else. curious if anyone has done better.
  - Bastian: I've had the same issue. The app moments had a workaround... it prompts you to take screenshots, and then the app can automate parsing from those.
- Mad: minor, but been using a paper sleep diary (consensus sleep diary) past four days
  - Dan: when I used AutoSleep I was impressed by the app's calculation of "sleep debt" - unclear what the algorithm for it was but it seemed to work really well
- Bastian: something to share re Apple Watch, was shared in the slack...
  - People exported data twice, and data from the same time period (!) changed between exports -- retroactive data change!
  - <https://www.beiwe.org/exporting-the-same-data-from-a-wearable-twice-doesnt-give-you-the-same-data/>
  - Mad: ideally data would be tagged with a version number of the algorithm used to generate it. Then it's at least ... less sneaky, and clear whether you're comparing data that may be different due to algorithmic differences.
  - Bastian: it raises concerns e.g. how we go about importing Fitbit data within Open Humans -- where we assume "old data" hasn't changed, we append rather than spending a couple days re-collecting years of data.
  - Dan B: it might be that the algorithm itself hasn't changed, it might be that a baseline data has changed over time leading to a recalculation
  - D G: if there's raw data available to recalculate, why not just give the user access to that?
    - Mad: size & need to delete is the usual reason for not trying to share raw data...
    - Bastian: for me this was the biggest surprise
- Joyce: I'm curious about what Ivet's working on
  - Ivet: academic work on a wearable that tracks muscle activity while training, to try to warn and prevent injuries for long distance runners
    - main issue for us has been that "running" is a lot more movement than the sensors were designed for

# July 28 (Tech Meetup)

9:15 PDT / 12:15 EDT / 17:15 BST / 18:15 CEST

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

## Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
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## Topics:

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## Notes:

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# July 22 (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: <https://tinyurl.com/2t77jst3>

## Attendees:

- Mad Ball\*
- Dan B\*
- Bastian\*
- Joyce\*
- Shelby\*
- Gary\*
- Steven\*
- Michael Becker\*
- D G\*

## Topics:

- Plan for QS show & tell on August 12
- Joyce - have data from a second experiment I could share, including CGM and blood tests / food reaction indicators
- Steven - not much, but thinking about how to be recording data about baby
  - Shelby - trying some similar stuff, was tracking some data w/ baby, reduced but maybe do new things
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## Notes:

- Michael - FYI doing a survey of personal data space & would be interested in talking to anyone here about things
- Joyce - sharing second experiment slides
  - (aside - wearing EEG right now, can see how anticipating talking affects me!)
  - can't give details about manual/device intervention, but this is tracking the effect of it
  - 4 day experiment; 1st and 3rd with intervention used throughout day
    - (graph 1) subjective symptom, minimum HR, "walking HR"; (graph 2) peak glucose after lunch and dinner
      - graph 2, peak glucose seems to be consistently higher on days 2/4. Hypothesis is that this is related to stress, food reactions.
    - (graph 3) urine pH seems less acidic when intervention is used
    - (graph 4) 10 ounce pepsi "challenge", tracking baseline and peak glucose response
  - long term (annual, 2011-2021) data tracking IgG4 responses to rice, beef, cow milk -- general decline since 2011. But unclear; can be affected by how much you're consuming a food. (e.g. increases from 2011 to 2013, maybe due to increased consumption?); 2nd graph wheat, corn.
    - also plotted an average of 15 or so foods combined that I thought representative, decline since 2013. I think it correlates with improved tolerance of these foods.
    - actually over 100 tested; also plotted how many were low/moderate/high, significant reduction in how many were "high"

- Gary: you see a change over time in these measures, was there an intervention?
  - Joyce: I attribute it to the approach I've developed, which has become the manual intervention that I've been developing as a medical device
- Gary: I know you don't want to reveal details, but ... is it something you do once a day, or a period of time...?
  - Joyce: I try to use it a lot during the day; I think it could be used for just 30m a day, or could be used e.g. while watching TV. I think it accomplishes what allergy shots would accomplish (although I don't have traditional allergies -- food sensitivities), an alternative mechanism. Also, allergy shots are only available for a narrow range of potential triggers. I think how it's working may be related to things like intermittent fasting.
- Mad: about the four day experiment, are you interested in doing more than four days?
  - Joyce: I want to do more, but it can be really challenging to control my whole day's behavior for potentially confounding factors e.g. activity level (keeping these all the same every day)
- Shelby: is the experiment also intended to explore altering aspects of the intervention, or just test and demonstrate it's having an effect? thought about any ways you might alter the intervention?
  - Joyce: I think I may have learned one thing that I'd want to try changing in the intervention; that wasn't my intent with this though.
- Joyce: I'm interested in the EEG as well, but I'm wondering what "normal" would look like, waiting for absence of symptoms
- Baby tracking - Steven (w/3 week old)
  - Steven
    - been tracking "inputs" and "outputs" - time of breastfeeding & duration, time of diaper changes.
    - both recording daybooks
    - also got the book "50 experiments to do with your baby", thinking I'll try to be structure, videotape them. 1st experiment, heel pricks w/ breastmilk applied to nose to smell, didn't seem to work maybe because
- Shelby
  - was tracking duration of feeding; similarly it's hard to track "how much" just via time. felt a need to pump and be able to track quantity. but that's making it hard to get nursing effective.
    - so I've given up on tracking time of breastfeeding, how long, since it's so hard to know
    - Mad: I used a [baby scale](#) and measured before and after - put on a fresh diaper, then measured weight again right after without changing the diaper - so any added weight must have been from the milk consumed
    - Steven: another aspect is knowing a feeding is "done" vs "partial" (and need to keep going) - checking if you're done
  - aside re bed-sharing - Steven: from exploring literature, if you remove cases like alcoholism and other extreme issues, the risk is a lot lower.
    - Gary: we similarly read the same literature, and ended up with baby in bed; reflecting on how hard it is to make individual decisions after reading public health research!
    - Mad: I ended up doing a lot of co-sleeping too... it's just so hard or unrealistic not to. ended up using this (or similar) <https://www.amazon.com/dp/B00BZAI1FO> ... and wrt to reading research, I remember being surprised at how SIDS actually starts low and peaks at a couple months



- Steven - reading guidelines and research has been helpful for guiding decisions. Another interesting aspect has been how some of them relate to cultural values.
- Shelby - thinking about tracking naps - have tracked one nap so far. I feel like it might be easier to do; but can be challenging due to where sleeping (while held, in bassinet, etc). but would be useful because I might be able to plan when I see patterns.
  - Michael: for our kid, we did track it, especially the timing of when they were
  - Dan: we didn't track, but had a lot of medical issues. ended up trying a theory on our own despite doctors not advising it, and this worked -- the issue was extreme difficulty with weight gain; my wife stopped eating dairy products, which seemed to be causing GERD
- 
- Gary - planning Show & Tell talks for August 12
  - Going to put event on QS home page, announce it in the meetup we manage (and others can copy if they'd like), and share on social media channels
  - Let's plan to use a different zoom link that's set up for this meeting
  - Presentations should be 10 minutes, total of 4 or 5 and lasting an hour and a half. (This is typical length. Could also keep it to an hour, less talks.)
    - Steven: I think plan on 90 minutes; if you attempt an hour it ends up lasting longer
  - Steven: how should people interested in presenting let us know?
    - Gary: I will follow up personally with anyone that wants to present; so any way you can reach out to me, that works.
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## July 15 (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: <https://tinyurl.com/2t77jst3>

### Attendees:

- Mad Ball\*
- Richard Sprague\*
- Enric\*
- Gary\*
- Joyce\*
- DG\*
- Bastian\*
- Dan\*

### Topics:

- Mad: brief Q related to new Halo & general "sleep tracking" consistency
  - Richard: would be curious about this

- Joyce: have some slides from another longer term experiment I could share, and an observation to EEG that's a bit interesting
- Bastian: brief thing about time tracking to share, plus we should talk about planning a S&T talks since we were planning to do it around now (keating memorial)
- Enric: no update, except general question about that I haven't been tracking, having a gap in data
- Dan: new, have a couple graphs could share
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#### Notes:

- Dan: have oura ring, apple watch, track calories using mynetdiary (which allows export on per food basis). am a data scientist, so I can add merge with more data regarding on the food.
  - use a c-pap machine; diabetes in the family so I think about that
  - Mad: I haven't used mynetdiary, it sounds like you really appreciate the per food basis?
    - Dan: yeah I've also tried myfitness pal, I wanted to try to have an anti-inflammatory diet & that was more possible to do with mynetdiary. Also like the home screen widget for mynetdiary. (<https://www.mynetdiary.com/>)
    - Dan: I also use shortcuts to connect the data to an app called [Charty](https://chartyios.app/) in iOS, that can embed them in homescreen or in morning report (<https://chartyios.app/>) so I can see these every morning (a quick view in the morning; I use R to build more detailed graphs)
  - DG - what sort of analysis do you do in R? how do you bin the data?
    - Dan: sharing graph of calories eating vs weight - have found exercise has little impact, 88% of weight change can be explained by calories
  - Richard: reasons for preference for mynetdiary?
    - Dan: it's mainly the widget, ability to create the widgets via food level export.
    - DG: might be interested in bitesnap
    - Richard: I looked around a year or two ago for the "best app" and ended up preferring cronometer pro, which was nice because it has timestamps
      - Dan: mynetdiary has this too
  - Bastian: can you enter data from the widgets on the homescreen?
    - Dan: mostly a shortcut to a screen on the app, not enter directly
  - Gary: this might be the best example I've seen of someone taking advantage of the data flow/integration around third party apps that Apple has been trying to enable
  - Dan: another integration I've added is related to a supplement I'm taking, ox bile, is something that pops up after I've logged eating, calculating and recommending how much to take after
  - Mad: does data flow through HealthKit, or directly from one app to another? Dan: I'm using HealthKit for all of it, mynetdiary is writing directly
    - Richard: how do you get the data out of healthkit? I've downloaded the enormous XML file, and it's huge and too large to parse
      - Dan: calories I export directly from mynetdiary; but the other exports tend to be quite limited - values for last seven days. Shortcuts "pull healthkit data from last seven days"
      - Gary: ah, so shortcuts can pull data from healthkit? Dan: sort of. Sleep isn't working. But with some other measures it works better. Have to be careful about things like aggregation.
    - Richard: I've been looking for something that lets me export the last seven days of healthkit data and haven't found a method for it.
      - Dan: I can share the shortcuts with you

- Gary: being able to see the impact of diet vs. exercise on weight -- to know that and see it -- could be the basis of a really nice talk
- DG: do you have a blog? github?
  - Richard: maybe join the slack
  - slackin.openhumans.org to join the slack workspace, which is at openhumans.slack.com -- in particular join the #self-research channel
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- Mad: wears three different trackers, now trying to compare a "minority report" among them
  - Halo seems to capture the least amount of sleep
  - Mad: Apple Watch has a serious issue though, it keeps thinking I'm waking when my alarm goes off, but sometimes I sleep in!
  - Richard: my experience is that the Halo has been more accurate about how well I've slept, compared to my subjective experience -- if good, above 80, it matches my subjective experience
    - Halo seems to give a big penalty for sleep disturbances
  - Gary: I think calibration experiments are really interesting -- maybe doing self-rating of subjective sleep experience for a while and compare it to these sleep trackers
    - Gary: I think it's getting at, if subjective experience doesn't match, I won't trust the wearable
    - Richard: tbf I'm not sure whether the app is affecting how well I think I slept. Not sure how I'd score 1 to 10
      - Bastian: maybe a binary
  - Bastian: note there's two different alarms, Apple alarm and then the "sleep schedule" within sleep tracking app
    - Mad: oh no, that's what changed! 2 or 3 weeks ago I had a prompt to use sleep schedule within Apple's "sleep tracking" app -- and I did, that sounded sensible! and now the tracking is screwed up!
- Bastian - update regarding time tracking is super fast - I use RescueTime to track time, and with the pandemic it was all tracking via the computer
  - after lockdowns though, it's a lot harder to track time when meetings aren't via my own computer. I was doing manual addition of events to rescuetime for a while, but couldn't keep it up.
    - set up a connection from google calendar to rescuetime, using IFTTT to add data from calendar to rescuetime. it does this at the end of a meeting.
      - so, when a meeting pops up but I'm not actually doing it, I make sure to remove the meeting from my calendar before it gets copied over.
- Mad: regarding keating memorial & talks, two questions are "when" and "who"
  - Gary: I would definitely like to give a talk, and a deadline would really help. I don't think I could pull it together in a week, but maybe two.
  - Mad: I don't feel like I'm able to give a talk, pandemic & post-pandemic has been too much of a mess to feel like I have an interesting self research experience
  - Bastian: I could give a talk about the blood oxygen stuff, which I could repeat, but maybe not interesting because it's been presented before, okay to have it as a backup if we have too few talks
  - Enric: looking forward to giving a presentation on my self research, up for doing it next week or later
  - Joyce: maybe not a good candidate depending on whether there's a concern about lack of details about the device I'm using as an intervention, which I'm unable to share because I'm trying to commercialize it
    - Gary: yeah, it might be possible to work around, but it's tough because you don't want to say "and then I did a magic thing" and people don't know what it is

- Richard: what sort of quality etc are we talking about here? are these just normal show & tell talks? is it a publication?
  - Gary: it's the same, same publication pipeline
  - Richard: it goes into the QS pile?
  - Gary: yes, same as any other S&T presentation
  - Richard: I always have something to present, I'd be happy to help out
  - Gary: main appeal is that a presentation can be a big help for people that want to put it together
- DG: presentation I shared a week ago, could update, but don't have analysis -- think it's not really good
- Asking people that aren't here? e.g. Kate, Abhik, message on Slack channel
- Gary: typically a 10 minute talk, really good talks are often 7 or 8 minutes (we used to be strict on this).
  - Most important things: slides should be illustrations of *actual* work done in the project.
    - device you've used, graph of your data, list of your questions
    - What did I do? How did I do it? What did I learn?

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# July 14 (Tech Meetup)

9:15 PDT / 12:15 EDT / 17:15 BST / 18:15 CEST

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

## Attendees:

- Mad Ball
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## Topics:

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## Notes:

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# July 8 (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: <https://tinyurl.com/2t77jst3>

## Attendees:

- Mad Ball\*
- Joyce Waterhouse\*
- Bastian Greshake Tzovaras\*
- D G\*
- Richard Sprague\*
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## Topics:

- Joyce - can present something I did with data, can go from 15 to 30 minutes
- Mad / Richard - can chat more about Halo (Mad just got)
- Dimitri - could talk about my symptoms, how I'm trying to use my data
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## Notes:

- Joyce - improvements through observations from a 30-year chronic illness ME/CFS
  - variety of observations: notebooks, measurements on myself
    - in last couple years, apple watch and later oura ring provided more objective data that was easier to present
  - history
    - at one point bedridden, underweight; noteworthy researcher, Ron Davis & son with severe ME/CFS and a book about them (Puzzle Solver)
    - illness started with various/complex events and factors - viral infections, stressful event, possible tick bites (lyme), mold?
    - in own efforts to improve this, working on commercially sharing an invention that may help others - automated version of what I did manually
  - analyses
    - four days data, using device day 1 & 3, not on days 2 & 4
      - comparing: urinary alkalinity, symptom scores (self score out of 100%), and sleep score (oura). behavior was generally the same throughout. sleep score didn't seem to change much in response to treatment.
        - pH graphed with "100%" as 8. note that diet remained the same; while this affects pH, this shouldn't affect pH; I'm measuring pH because I think it's reflecting inflammation reactions, which I've read about in the past
      - also looking at walking heartrate and RHR; walking heartrate seems most affected
    - past 2 years of oura sleep data - "deep sleep" increased, RHR has gone down
    - hypothesis based on this data: many reactions occur to manmade chemicals (e.g. plastics). Also, that microbes themselves are triggering allergic reactions and allergic cross-reactions.

- written articles that are online as preprints, but hasn't so far been accepted for publication in a peer reviewed journal
- <https://www.researchgate.net/scientific-contributions/Joyce-Waterhouse-2185794675>
- D: what did you use for acidity testing? J: Hydroin test strips, usually the one that goes 0 to 8.0.
- D: are there only the four days of data?
  - J: this was just a specific experiment; I did the same experiment again a month later and got similar results. Past work I haven't had devices to give objective data, just own notes. (As an aside: in the past, I tried a fitbit but I was having a reaction to it.)
  - J: this past month have added CGM and EEG to collect more objective data; also working with a lab that does blood tests of microbes.
    - in a test so far, found "nothing but a microbe that's probably a contaminant", but in published research this researcher has reported enrichment of that microbe in ME/CFS. these aren't typically reported as they're low level, not sepsis, but I think there may be something to the "normal levels"
- M: I was curious about the walking heartrate measure, how you collected that
  - J: would control my pace by timing the walk, keep the same distance vs. time. I've found standing is also very correlated.
  - M: standing seems interesting as there's less you could do to influence it
  - J: I think there's issues with heartrate in general comes from the book "Pulse Test" (Arthur Coca)
- Dimitri - sharing an app for self-reporting symptoms & data I've collected with that
  - mySymptoms app  
[https://play.google.com/store/apps/details?id=com.sglabs.mysymptoms&hl=en\\_US&gl=US](https://play.google.com/store/apps/details?id=com.sglabs.mysymptoms&hl=en_US&gl=US)
  - example: recording nausea, vomiting, etc. at 0-10
  - looking at my data, recorded over time - compulsion, daydreaming, dizziness, energetic, headache
    - (aside on data issue - there shouldn't be so many compulsion/daydreaming data)
  - when recording symptoms, it's not the specific moment - e.g. dizziness might peak for 10 minutes ... when I do this, I try to take into account the past four hours. Self-reporting happens whenever I remember to do it (e.g. right before bed, once in middle of day)
  - Mad: any hypotheses? ideally what you must want is to figure out if there's anything you can do that would affect symptoms
    - D: I'm really unsure; dizziness has completely gone away. I think rocking and daydreaming should be positively correlated.
  - other graphs: eye strain, socialization, spine pain
  - M: it can be helpful to do hypothesis generation, to guide what forms of analysis to use
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## July 6 (Community Call)

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: <https://tinyurl.com/376na2bk>

Attendees:

- Mad Ball
- Bastian Greshake Tzovaras
- Dimitri (D G)
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Notes:

- Dimitri - for assessing models I'm working with, I need data where I have the causes and effects.
  - in time series data, how to determine correlation? how to determine causality?
    - challenging when e.g. there's only two events that occurred
  - frustration with time series is "autocorrelation" - not correlation across different types of data
  - Mad: maybe mapping data to percentiles so they have a common scale? Dimitri: this sounds like auto-correlation and ... relies on data having similar distributions (e.g. normal)
  - Bastian: easier if there's discrete interventions in the time series; looking at time series relative to the events
    - Mad: reminded of regression discontinuity analysis
    - [https://en.wikipedia.org/wiki/Regression\\_discontinuity\\_design](https://en.wikipedia.org/wiki/Regression_discontinuity_design)
  - Bastian: also reminded of Herman de Vries Oura analysis, <https://hermandevries.nl/2020/09/23/relationships-between-hrv-sleep-and-physical-activity-in-personal-data/>
    - also here (I adapted his code into a notebook) <https://forum.quantifiedself.com/t/relationships-between-hrv-sleep-and-physical-activity-in-personal-oura-ring-data/8524/3>
    - Adapted code at <https://exploratory.openhumans.org/notebook/165/>
  - Mad: as a high level reflection, I'm sure you're already aware, but to keep in mind that passive data to generate hypotheses for correlation can be very complex and limited; interventions when possible are a powerful tool
  - Bastian: also a reflection is to look at neuro data analysis, which are very time series based and maybe not always EEG (e.g. combining GSR with EEG)
    - ... and maybe to reading about correcting for multiple hypothesis testing
    - Mad: it's the danger of passive data, generating infinite hypotheses -- but it can create promising hypotheses for later testing via intervention
  - D: would love to brainstorm potential challenges in data & noise
    - M: for example... gaps that aren't random, they're caused by some environmental / life thing (e.g. stress or busy, travelling), and if there's still other data that \*doesn't\* have a gap may be affected by the same underlying situation contributing to the gap
      - non-random gaps, e.g. under stress. e.g. mood logging missing when stressed or unhappy.
    - D: having self-reinforcing events, e.g. a bad habit that triggers self-repetition; M: and gary sensing self-reinforcement in arrhythmias
    - D: also, qualitative scales being locally consistent (a "2" relative to yesterday is fairly consistent) but over time a "2" may mean something different many months later
    - B: habituation D: similarly, hedonic treadmill M: attenuation - can be due to physiological or psychological adjustment
      - M: I think it's noteworthy that internal reporting is really tough to know "reality" on, but that physiological measures are aren't very influenced by "belief"



- M: a broad observation is that secondary use of data can be very challenging; it's primarily useful for the original purpose it was collected (as what and how it was collected was designed for that purpose; and biases that relate to that)
- B: another challenge that's common is change of devices - e.g. using different heartrate monitors over the years; discontinuity occurs. Even though in theory wearing devices at the same time could control for this, slight variations in positions can make big differences. (Works if you never do change the position, but...)
  - e.g. just two different oura rings...  
<https://forum.quantifiedself.com/t/comparing-2-oura-rings-for-2-weeks/7789> ...  
 some like heartrate didn't change, but others (e.g. sleep latency!) were totally different
  - M: variation in devices is really tough - within an individual it's not such a problem -- as long as they're comparing/viewing within the same device, which is usually what's happening. But for aggregate, or a long time scale for the individual, it's really hard. Academic researchers get around this by *not* doing it: they buy the same device for everyone to use.

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## July 1 (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: <https://tinyurl.com/2t77jst3>

Attendees:

- Mad Ball\*
- Bastian Greshake Tzovaras\*
- Holly Williams\*
- Scott Williams (no relation)\*
- Joyce Waterhouse\*
- Katarzyna Wac (Kate)\*
- T.A. McCann\*
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Topics:

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Notes:

- Joyce: curious what "marker" is most valuable to everyone?
  - Joyce: for me, I think RHR is most important. But also, RHR with activity (which are related)

- Holly: what is your preferred method for it? Joyce: Apple Watch these days... I used to do it for myself. And I've tried a Fitbit, but I had to keep prompting it to measure while the Apple Watch would do it passively.
- Holly: my Apple Watch is series 3 ... is yours more recent? Joyce: probably, I just got it a couple months ago
- Kat: I really didn't like the low battery for Apple Watch. I've mostly switched to Oura ring, in part also because I'm really interested in overnight measures. From this, RHR and also the shape of overnight heartrate graph overnight (e.g. if it lowers later, due to stuff like alcohol metabolism). Also HRV. Recently could see effects of second vaccination.
- Mad: I think for me the most day-to-day valuable data I'm using is my sleep tracking (which I'm also using Oura for)
- Bastian: I'm with Kat in primarily liking the Oura, for understanding overnight sleep. In particular I really like that it prompts resting, not always "more exercise". But for tracking exercise the Oura ring is bad and use the Apple Watch instead
- Holly: I was really happy with the Amazon Halo for sleep tracking. I did try the Whoop band briefly, but ended up not keeping it due to subscription fee.
- TA McCann - sharing a podcast about whoop, planning to try it based on this <https://podcasts.apple.com/us/podcast/will-ahmed-optimizing-human-performance-founders-field/id1154105909?i=1000526724350>
- Bastian: regarding Apple Watch ... I've actually been using two to get around battery life issues, switching to the newer one overnight (as SpO2 is only relevant when resting)
- Mad: what are active data collections that people find useful?
  - Joyce: I write a lot down during the day, about what I eat and do. I'm not very systematic about it.
  - Mad: do you use paper, or an app? Joyce: I do an email to myself every day.
  - Joyce: I don't like relying on any one thing for records, I worry about losing them - so I really like to have backup plans.
- Joyce: something I've been doing you might find interesting is, measuring your urine pH -- which I was interested in because it's been reported as useful for detecting and measuring food reactions. Acidity reflecting inflammation from the reaction.
  - Mad: have you found things that aren't food reactions that also affect it? Joyce: I've also observed what look like reactions to inhalants. Timescale depends on absorption.
- Mad: I do like mood tracking, but at the same time find a lot of frustrations and limitations in it
  - Holly: one thing I tracked in 2015 was journaling, and put this through IBM Watson for personality inference scores, and could see how those were changing over time. I think it helped to see that things were changing -- it was a difficult time for me, and it helped to have confirmation that things \*had\* changed
  - Mad: I think it's interesting to see "overall this has changed, I didn't imagine that" Holly: it was also helpful to see that I was prone to not realizing negative periods weren't as prevalent as I was inclined to think when in a negative mood
- Mad: I'm increasingly curious about the Halo, in particular the "mood" tracking based on "tone of voice" -- is this useful, Holly -- have you explored this?
  - Holly: frustratingly it gives an overall measure for the day, and I wish I could understand more about what's happening at different times, e.g. at work vs with friends, etc.
  - Holly: it looks like it has more refinement now, e.g. peak mood during day, mood split by hour -- maybe there's more potential than I'd realized, I hadn't looked at it in a while
  - Joyce: I'm curious about the categories, if it can say "you sound stressed, you sound anxious"
    - Holly: four main categories.... I'd like to explore it more in the next week
    - Mad: it sounds like happy/active, happy/inactive, unhappy/inactive, unhappy/active.

- Mad: it sounds interesting to be able to break it down with more detail... we all know that we aren't always expressing our "true selves", so how we're feeling internally might show up or change more in some contexts over others
- Holly: I'm going to check out the download option, see if I can explore mood data in the download. It doesn't hook up to a lot of things by itself.
- Mad: I'm really curious now about it, and maybe to compare my own tracking notes vs what Halo thinks is going on
  - Holly: what do you use? Mad: iMoodJournal, but it only captures one dimension, which is a limitation. Bastian: maybe you could set up Reporter App to capture two dimensions.
- Joyce: I'm curious about galvanic skin response...
  - Kat: I can say in research, it's been used in psych for arousal (without detecting positive vs negative, just arousal)... and then see contexts elsewhere. I've seen it used for predicting seizures for kids. GSR is very sensitive to activity.
- Bastian: in terms of new things potentially of interest or to try, I saw the CGM freestyle libre "sense" ... a collaboration for fitness people that's connected to garmin -- for sports rather than medical use
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# June 30 (Tech Meetup)

9:15 PDT / 12:15 EDT / 17:15 BST / 18:15 CEST

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

Attendees:

- Mad Ball
- Vytenis Darulis
- Bastian
- ~~Enric Garcia Torrents~~
- Mike Sinn
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Topics:

- Mad - no particular topics, small updates + want to talk about scheduling
- Mike - no updates
- Bastian - no updates
- Vytenis - no particular topics

Notes:

- Mike: Vytenis, can you tell us about your project? Called DataMe?
  - Vytenis: we've integrated fitbit, apple health, spotify now
    - What we're doing: a bit similar to open humans, wanting to collect various data sources, and add artificial intelligence to create advice for people. Also similar to what
    - website: datame.app
  - Mike: who's involved? I think I joined the whitelist, curious if we'll be able to try it
    - Vytenis: started with YC startapp budget. Made a small MVP for this, looking at how to potentially move forward. Have a partner (hasn't attended OH meetings)
  - Mike: I'd be interested in seeing a demo if you have one to share
- Bastian: been focused on getting papers submitted / resubmitted lately before europeans leave for summer
- Mad: been getting back into thinking stuff & working with Bastian on papers
  - low level tech goal, get my notebook script running again to clean spam
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# June 24 (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: <https://tinyurl.com/2t77jst3>

Attendees:

- Mad Ball

- Joyce Waterhouse
- Steven Jonas
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Topics:

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Notes:

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## June 17 (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: <https://tinyurl.com/2t77jst3>

Attendees:

- Mad\*
- Joyce\*
- D G\*
- Richard\*
- Enric\*
- Gary\*
- Steven Jonas\*
- Valerie\*
- Bastian\*
- Abhik\*
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Topics:

- Richard - interested in migraines, would like to discuss
- Enric - would like to share something about intervention I did in May, did some visualization
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Notes:

- Richard
  - Helping someone that's had regular migraines for past couple of years, and have been working with her to try to figure it out.
    - Looking at ketones... trying a ketogenic diet, on theory that migraines might be caused by energy changes in brain and maybe being in a ketogenic state would make them less likely or severe.

- Looking for patterns of blood glucose (low in ketosis) vs migraines; hard to see any pattern so far - two migraines, both in periods of very low blood glucose
- Also looking at CGM data
- Steven: what sort of knowledge is out there connecting blood glucose to migraines?
  - Richard: there are people that claim this - following a strict ketogenic diet can eliminate migraines. In academic literature, some people follow a ketogenic diet can experience some relief.
  - Richard: but I also see things like... about electrolytes, it's sodium and potassium, it's the balance of these, etc.
- Steven: maybe of interest, Jim McCarter on spending a year in ketogenic state (this is probably our most popular video! it gets shared on ketogenic discussion boards etc.) <https://quantifiedself.com/blog/effects-year-ketosis-jim-mccarter/oh>
- Joyce: maybe of interest is the book "heal your headache" which discusses various influences. I know someone the book helped, I think in particular stuff about hormonal patterns. With respect to food sensitivities I think it can be hard to figure out because there can be cumulative issues. Also there can be delayed effects in responses, e.g. to stress.
  - Joyce: also recommend Arthur Coca, M.D. The Pulse Test, available free as pdf at [soilandhealth.org](http://soilandhealth.org)
- Mad: it sounds like you've ruled out simple interventions or explanations, like dehydration.
  - Richard: yes, tried that. When something works, it works. We've tried all these and none of it has been an obvious slam dunk. If it were, we would've figured this out by now.
- Gary: a suggestion that might be useful on the protocol side... I think for some of these complex things which are the result of a cascade, a number of things come into play ... it can be helpful to observe something "higher up" in the cascade that's more frequent, because you get more data, more events. Don't know if there's anything like that here, like a mild headache that sometimes precedes a migraine.
  - Richard: I know in her case sensitivity to sounds, light can precede it.
  - Gary: was thinking about a one button, maybe there's a feeling like "the light is too bright" or "people are being too loud"
- Steven: another example... Mark Drangsholt and Case Crossover Design: <https://quantifiedself.com/blog/qs-primer-case-crossover-design/>
  - Gary: I think this showed the value of a checklist. That is, a method that (1) is looking back at a *defined* period (e.g. last hour, last 24 hours) and (2) fill out a checklist of items that were true in that preceding period. With this formalization it becomes easier to collect data that's easier to interpret later.
- Richard: something I know I've had is the scintillating scotoma... and these are interrelated to migraines
  - [https://en.wikipedia.org/wiki/Scintillating\\_scotoma](https://en.wikipedia.org/wiki/Scintillating_scotoma)
  - ... and there's interventions that seem to work for me, and I wonder if they're relevant for her. And it makes me wonder if there are other neurological malfunctions that aren't "painful" but are going on, but we don't recognize as migraines.
- Enric - intervention I did in May, related to discussions in previous meeting
  - observing smartphone "dependence" ... using a one-button (puckjs) to record positive & negative impulses to use my smartphone
  - 3 to 20 May, collected 755 datapoints via one-button, but one-button tracker failed. Cleaned this and have 268 "valid" data points, excluding extremely long or short presses that look erroneous or suspicious. (e.g. one for 3000 seconds, probably not "real"! short is suspicious because I always tried to press the button for at least a second.)
  - Notes from the presses, ~9000 words worth.
    - [https://backlogs.net/interventions/plot\\_enric.html](https://backlogs.net/interventions/plot_enric.html) (made in python with plotly library)

- "negative" / "positive" / "question" impulses. default is to consider impulses to use the smartphone as negative. third category, there were some things where I didn't feel able to categorize as positive or negative...
- An example of negative experiences, frustration with trying to use the phone e.g. to access a browser or email and it not working.
- Positive uses, e.g. listening to radio while waiting for someone
- Steven: can you walk me through the annotation process? How are those added to the single button recording?
  - Enric: I had a paper notebook with me, made a note as soon as I had a chance. Moved to writing on a digital tablet, which does a fairly good job of text recognition but still needs to be checked.
- Steven: what was the motivation for switching to "dumb phone" - was it curiosity, or a more specific sense that the smartphone was bad for you.
  - Enric: I remember doing it some years ago, and wanted to understand better what that experience was like. But also curious about "digital minimalism" -- not a term I was familiar with until I was already doing this.
- Bastian: you mentioned you found a way to continue but didn't mention it -- I think it'd be interesting to discuss alternative.
  - Enric: I've been looking at a simple audio recorder, which has a timestamp on the audio file and then speaking rather than writing. Need to map the audio to words, but I think that would simplify the process of recording.
- Enric: if I'd read the digital minimalism book beforehand, I would've benefited from knowing what I wanted to pay attention to before already being in the middle of it.
- Steven: one thing I'm currently doing is trying to have two devices - "self tracking device" (only me entering information) + "phone" (information from elsewhere)
  - Steven: e.g. notifications on apple watch, which became the "self tracking". Notifications used to feel a bit stressful, and after a week or two I realized notifications weren't going to be messages from elsewhere and weren't so stressful to receive.
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## June 16 (Tech Meetup)

9:30 PDT / 12:30 EDT / 17:30 BST / 18:30 CEST

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

Attendees:

- Mad
- Mike Sinn
- Vytenis

- Bastian
- Paula

Notes:

- Mike: which template to start with?
  - Been using this: <https://github.com/OpenHumans/oh-data-source-template>
    - This looks very dated, old Python and Django
  - Bastian: some better suggestions
    - <https://github.com/OpenHumans/oh-data-demo-template> - more modern, although not using the django-open-humans package
    - <https://github.com/OpenHumans/oh-overland> an integration that uses Django2, Celery + django-open-humans
    - About the django-open-humans package: <https://django-open-humans.readthedocs.io/en/latest/>
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## June 10 (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: <https://tinyurl.com/2t77jst3>

Attendees:

- Mad\*
- Joyce\*
- Holly\*
- D G\*
- Enric\*
- Mike Sinn\*
- Bastian\*
- Abhik\*
- 

Topics:

- Abhik: working on Muse import, can share some updates on this
- general topic: Keating Memorial deadline?
  - announced on QS website is 22nd of July
- Joyce: Also some Muse updates
- Mike: can share various my various analyses on food etc and effects
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## Notes:

- The Open Humans slack is at: [slackin.openhumans.org](https://slackin.openhumans.org) and we have a #self-research channel there
- Holly - using google data studio to collect and use tracking data, creating a scoreboard
- Memorial & deadline
  - Steven Keating passed away on July 19, 2019. We do our project presentations on July 22 (first Thursday after the Anniversary)
    - Format will be like other Quantified Self Show & Tells, focus on 3 questions: 1. What did I do? 2. How did I do it? 3. What did I learn?
  - Need to schedule with Gary
- Abhik:
  - Working on data science for using the Muse data
  - Muse Monitor gives back a huge spreadsheet, trying to split data
  - for July, wanted to look at brainwave tracking vs. tracking via wearables for sleep stage tracking
- Joyce - looking at how things like eating affect brainwave patterns
  - for a time I thought I'd observed a brainwave change in response to eating
    - but lately, patterns seem completely different, which seems to contradict that hypothesis
    - instructions didn't say that there's a magnetic clasp that shouldn't be put over the head, as it can stretch the sensors. Looking at sensor connections, they seem to be getting worse. Currently in the process of getting a new band... but, don't think this was responsible for the change.
    - protocol has been: consume a food and wait 30 seconds (chewing messes up reading) to look after
  - one thing I wonder about is masking, long term changes; e.g. stop eating a food, start feeling better - then eat it again, and really notice the effect (more reactive). Also, wondering about withdrawal reactions when you first stop eating a food (e.g. caffeine).
  - Abhik: it sounds like you have a solid food tracking setup; is it in a spreadsheet? how do you go about it?
    - Joyce: I've had trouble using special tools for this, so currently I just put it in my daily notes for the most part
  - Mad: I was wondering about timescale, since you mention looking right after chewing, but it takes time for food to absorb, have an effect
    - Joyce: haven't looked at larger time scales, one problem is that the muse has a limited battery life, battery dies after a night worth of use
    - Abhik: fwiw I have two ... I switch between them while the other is charging
  - Enric: I haven't seen these tools; do they need to be calibrated before you can start using them?
    - Joyce: nope, but they tell you that you can not easily compare between people but should compare it with yourself
  - Abhik: Did the Muse warranty process work out for you?
    - Joyce: after a while yes
  - Mad: I'm getting curious about the kind of data, thinking about ADHD: Can one see the impact of medication in the EEG data?
    - Abhik: Not sure if I've seen it in literature. EEG data isn't useful for a lot of things, but sleep & general focus/alertness works quite well. Can tell if you're focused on something in particular, or not focused on anything on particular.
      - It also measures things like jaw clenching and blinking ... and blinking is itself a measure of focus, you blink less when you're focused

- Bastian: it's so sensitive to movements so my understanding it doesn't work well unless you're sleeping or sitting
  - Abhik: I've found it's surprisingly working well while walking around as long as I'm not touching it
  - Joyce: mainly affected only if you do something that affects your face, e.g. chewing or touching it
- Mad: it has me reflecting on the limitations that might exist on whether a qualia is measurable ... for example it's not necessarily a lack of focus, but an inability to shift focus
  - Abhik: I know with more extensive brain imaging one can see different networks, but don't know whether it can be seen in EEG alone and brain waves
  - Joyce: I've noticed hot flashes have a dramatic effect on brainwave data
- Abhik - one thing I've been trying to figure out is artifacts where my activity tracker says I'm awake - I've set up a video recording but haven't looked at it, what was my EEG doing then.
  - Bastian: fwiw with my audio recording, I knew I was moving around not from a video, but because I could hear bedsheets and movement on the audio
- Bastian: here's a review article on ADHD and EEG  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4633088/>
  - *"The most robust EEG feature associated with ADHD is elevated power of slow waves (4–7Hz "theta") and/or decreased power of fast waves (14–30Hz "beta"), typically recorded over fronto-central electrodes, which are sometimes combined and quantified by the theta/beta ratio (TBR) [8, 9]. This conclusion was bolstered by early reports of medium to large effect sizes, ranging from .62 and 3.08 [10–12], for group differences in TBR and of diagnostic sensitivities and specificities in excess of 90% in multiple reports"*
  - The article is a bit old (2015), so there might be newer work
- Mike - diving into my own analyses of food & effects...
  - I think Joyce mentioned legumes, nuts? Joyce: yes, peanuts in particular.
  - Mike: I don't have regular peanuts, but I can look up butter toffee peanuts in my data
    - using the quantimodo tool, no strong effect ... maybe looking at something else
  - Sleep quality vs mood
    - these seem more correlated rather than causal
    - "sleep quality" is described by amount of movement during the night as measured by the fitbit accelerometer
    - correlation seems to be, if mood is better during the day, the following night has better sleep quality
  - Joyce: the effect on sleep can be confusing -- I think I've had cases where I have "better" sleep efficiency because I'm actually feeling more ill and sleep more
  - Mike: for me, my hypothesis on why it occurs is that serotonin is related to melatonin
  - Mad: it occurs to me that there's a lot of hypothesis one could come up with, e.g. when unhappy one may self medicate with alcohol which disrupts sleep, or lower happiness is associated with stressful ongoing events that make it harder to sleep, or when unhappy one goes to sleep later ... have you explored various hypotheses?
    - Mike: alcohol hasn't been an issue... one I was curious about was temperature interrelating to these, outdoor temperature, seasonal effects
    - Joyce: another potential seasonal effect is that I think allergens can disrupt sleep
    - Mike: it's interesting that your effects seem to be acute, while my effects seem to be delayed, e.g. for gluten intake it shows up two days later
  - Mad: do you have any cases where you found something in the data that prompted an intervention? Was gluten a case like this?
    - Mike: Yes, i tried cutting out gluten and observed improvements in a couple of dimensions. Also observed this with doing reintroduction experiments
- Mad: btw write up on Impossible Burger

- <https://forum.quantifiedself.com/t/investigating-potential-adult-fpies-food-reaction/9320>
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## June 3 (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: <https://tinyurl.com/2t77jst3>

Attendees:

- Mike Sinn \*
- Mad\*
- Bastian\*
- Joyce\*
- Valerie\*
- Dimitri (D G)\*
- Katarzyna Wac (Kate)\*
- David\*
- Steven Jonas\*
- Richard\*
- Enric\*
- Anne\*

Topics:

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- Bastian - update to share on my self research project if we have time, with slides
- Steven - a couple updates, no data, regarding experiments with controlling feeds, fasting
- Mike - nothing in particular, a couple studies I've created if we have spare time
- Anne - happy to answer questions about eczema solving project, guidance on how to move to a project that helps people do similar
- 

Notes:

- Bastian - snoring, wondering if it's related to blood oxygen saturation values
  - noticed nighttime blood O2 values were lower during the night, overall distribution is lower (and statistically significant difference), wondered if it was related to snoring
  - tried recording snoring with a tool that records only when you snore
    - but ... only triggered and recorded due to the dog moving around
    - 2nd try, record full night of audio through the night with voice memos app
      - (note voice memos doesn't note when it "starts", just end, which was annoying)
      - got two nights matched up this week
  - classified data of "snoring" times vs not snoring
    - no clear difference
  - separating type of snoring...
    - "loudest" snoring had some of the highest O2

- moving around recorded, seems around time of O2 recording, confounding in various ways (hard to tell if also snoring, O2 reads less accurate due to movement)
- conclusion: binary snoring yes/no classification might not be ideal. not sure I'll be doing more on this. ideas that aren't having to go through full night records
- Richard: what were you hoping to learn, what would have been a success?
  - Bastian: if I found the snoring "causal" then I'd see something to work on. And ... "should I worry about this (the O2 readings overnight) or is it an artifact?"
  - Richard: it'd be cool if the O2 levels predicted snoring, that'd be cool, but it sounds like it's not that simple, it's more complex
  - Bastian: there's a lot less data gathered during the day ... it doesn't collect when moving ... maybe there's more data and more artifacts at night might be that it's calibrated to avoid recording due to awake/daytime movement.
- Anne: I think it might be interesting to look at respiration rate, see if that's interrelated to blood O2.
  - Bastian: one thing I noticed, if your breathing pattern isn't "normal" the blood O2 won't occur / error ... seems like it's very careful about what conditions to do measures
- Gary: observing Apple says it won't record due to movement
  - Bastian: yeah, it uses 30 second windows, unclear "how much" movement causes it to abort. But also it only records every 30 minutes overnight.
  - Joyce: I discovered you can increase the frequency but it wears the battery out really quickly. Also ... I wonder if loud snoring is "deeper sleep", not moving, accounting for "better" oxygenation
- David: I have sleep apnea, my wife forced me to do a sleep study... the machine does record data, I haven't looked at it. What changed is my sinuses are less inflamed, can breathe through them now - nasal hasn't clogged as much as now. And it's also a cause/treatment for arrhythmia.
- Mad: given how rare the data is, not fine grained, have you considered getting a more continuous measure like a wellue ring?
  - Bastian: yeah, I think that a more continuous data for O2 might be the next step
- Enric: do you think the vacation vs. home made a difference?
  - Bastian: mainly the data is cleaner, less background noises like sirens on the street
- Anne: might be easier to find "snoring" in audio data by running an FFT over the data. One thing I've tried has been using a mouthguard to stop my snoring, and it's helped changed that.
  - Bastian: might be an easy intervention to see if it makes any impact
- Steven - small updates on things I'm trying, observations that might be interesting
  - with fasting... partly of interest because I gained 25 lbs during pandemic. In particular interested in the "fasting mimicking diet"
    - this requires more preparation though; so in the meantime I tried "one meal a day fasting" - breaking fast at 6pm and restarting at 8:30pm, very extreme version of intermittent fasting
    - been doing this for two weeks now. Observation: it's been surprisingly easy.
    - Trying to learn about long term effects, mindful of this.
    - Tracking the lengths of fasts, comparing to weight changes
    - Noticing "high heartrate" notifications from Apple Watch, curious about this
  - social media, trying to reduce time spent - infinite scroll is bad for me, try to remove this if I can.
    - the way social media is set up, it seems to stimulating, trying to change my use of thees to reduce that
    - tried saving all the subreddits I subscribed to as bookmarks, removed that subscription so I have to look at each bookmark rather than via the reddit app

- discovered my use became more deliberate: which community have I not checked in on
- yesterday applied this to twitter, broke it into separate accounts ... I found it interesting how less engaging the experience was
- This data is all tracked in RescueTime, I'm curious about whether time spent on these apps/sites changes
- And also tracking via journaling, writing down self observations
- Gary: how did you break twitter into separate accounts?
  - Steven: I created a folder with bookmarks for each person I follow, rather than using the feed Twitter provides
  - Gary: it's interesting because you're interested in reducing amount of time, but there are other things that might change in how you consume
- Richard: I think Twitter lists are the way to go. I have a private list called "top" that are the ten or so I really care about. Another called "quiet" that tweet rarely, so I want to deliberately check on if they've posted anything.
  - Steven: I've tried it and ... it's never worked out for me such that I feel good about my engagement with the platform.
  - Richard: my anecdotal experience has been that Twitter is a sort of time saver - I learn about stuff this way, rather than trying to read "news things" - I think it's important to look at it holistically, compared to time spent reading e.g. a newspaper.
- Mad: rather than just "too much time spent" ... it seems like there's an important difference between time "well spent" vs time "wasted / poorly spent" ... maybe this is something that might be captured by journalling
- Richard: something that might be interesting from a self quantification perspective... if there were some way to gather all the data/information that comes across my screen ... every tweet I see, information in webpages ... I wonder how it would be classified (political, scientific, about cryptocurrency, etc) ... I'd be interested in learning that
  - DG: try word2vec.
  - Richard: but where would I get the data, that's captured all that text. DG: if you find out, I'd be interested.
  - Mad: I wonder if most of this might be done via a browser extension that's dumping that text to a file
- Steven: something that's interesting to me is how I engage with the content. For example, during Trump era stuff the content would often stress me -- but I'd go to it when I was feeling stressed. I felt something similar on Facebook, seeing updates would lead to self comparisons and that stressed me. But I'd go to people's pages when I wanted to find out what they were up to, and I didn't react the same way ... there was something different about "I'm going to go visit, going to go find out what they're up to" rather than passively being bombarded with that content.
- Joyce: regarding the fasting - had you read Valter Longo's approach? He suggests skipping lunch regarding long run issues. Also, I've heard about an interesting approach called "bright line eating"
  - Steven: it's interesting to observe my impulses, and I was surprised that being hungry was more tolerable than I expected
- Mike: some studies I did on myself
  - energy vs. lunch ... it seems like higher energy associated with skipping lunch
  - washing sheets in previous weeks vs. mood ... positively correlated
  - above average social media use correlated with lower mood in following days
  - Steven: how do you record mood?
    - Mike: I've been using a 1-5 score

- Steven: I've used moodscope in the past, but time consuming ... how many times per day?
  - Mike: 4x per day, I used to use moodscope and tried importing but have switched to a simpler method
- Steven: how long ago did you find out about the lunch vs. mood
  - Mike: just looked at it today, so it hasn't yet changed my behavior
  - Steven: do you think it will?
  - Mike: the size of the effect is less than I expected ... and unsure if it's an effect, or correlation.
- Anne: I'm curious about diets that try to regulate hormone levels ... not recommending these because they can result in a rebound when you stop, but I'm curious. e.g. the Faigin diet. Wouldn't recommended; really intended for body builders... but it seems very illustrative of how eating is related to hormones.  
<https://www.davedraper.com/faigin-natural-hormonal-enhancement-excerpt.html>
- Gary: in some projects we've seen, people measure the effect of how one is taking the measurement on the correlation coefficients... for example, if you recorded have 3 days of 4 measurements each, and inconsistency and noise in making those few measurements ... the noise and inconsistency in how the measurements are made can mean that a small amount of data can result in "effects" and correlations that turn out to be dominated by "noise"
  - Mike: I try calculate z scores ... also, try to take into account number of measurements by sorting the correlations according to the amount of data
  - Gary: I'm curious what you see that overcomes the uncertainties
  - Mike: having a lot of data seems the only way to overcome it
- Gary: fyi for folks, I had a conversation with someone at Oura, if anyone is interested in more fine grained respiration rate data... let me know
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## June 1 (Community Call)

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: <https://tinyurl.com/376na2bk>

Attendees:

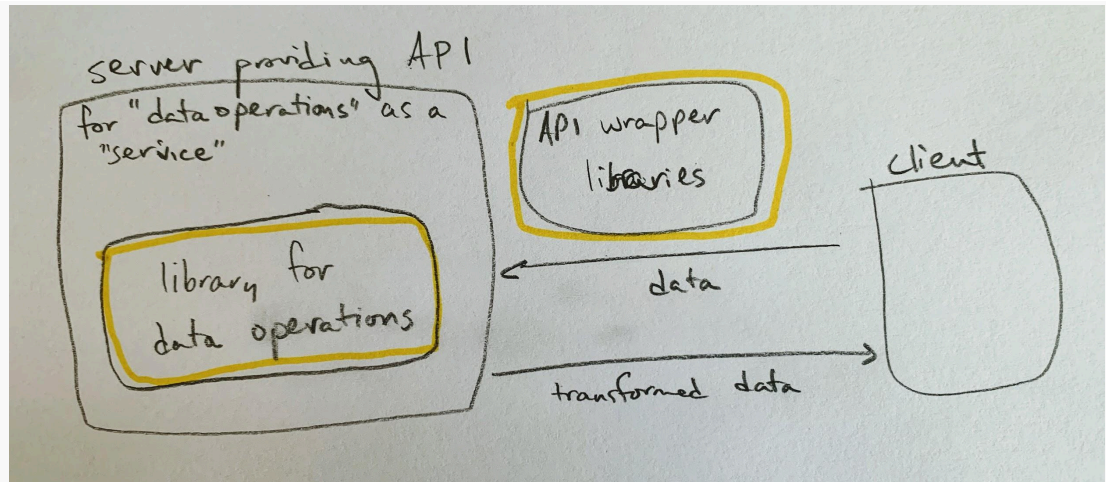
- Mike Sinn \*
- Mad Ball\*
- Vytenis
- DG
- Dave\*
- Vincenzo\*
- Bastian\*

Agenda:

- Mad: sharing a sketch of proposed "design" for something that might help with data analysis/processing tasks
- Mike: interested in an API for Open Humans that would be like an open source version of Human API or Validic

Topics:

- organize and structure data to make it easier to use
  - Mad's sketch of proposed thing to build:



- **Standardized Temporal Personal Data**
- **Mike:** OpenAPI specifications are currently the most widely used standard starting point for designing the APIs. You can use OpenAPI specs to describe all the models and the endpoints that return or accept them. The same OpenAPI spec file can also be used to generate the API server, the client SDKs for different languages, and interactive API documentation.
  - Shall we start with a rough draft Open API V3 spec I created at <https://github.com/mikepsinn/open-humans-standardized-api/blob/main/open-api-v3.yml> ? It's got way more than is needed currently, so we could go through it and I can explain what's there and people could suggest what they want to remove, add, and change (or make pull requests to do so). We can transfer this repo to the OH organization if you desire. <https://stoplight.io/> has a very nice visual editor you can use to edit it as well.
  - [OpenAPITools/openapi-generator: OpenAPI Generator allows generation of API client libraries \(SDK generation\), server stubs, documentation and configuration automatically given an OpenAPI Spec \(v2, v3\)](#)
- **Measurement Properties**
  - start\_datetime (ISO 8601)
  - end\_datetime (ISO 8601)
  - value (float)
  - source\_name (string)
  - unit (string)
  - creation\_datetime (ISO 8601)
  - variable\_name (string) - Example: Pain Severity, Blood Glucose
  - Note (string) - tags

Notes:

- Mad: sharing sketch, note that Open Humans isn't in the sketch - this is to provide something that's generally useful that isn't dependent on buy-in to Open Humans.



- Bastian: concrete example of use?
  - Mad: e.g. running a notebook (jupyter or observable) that is running on a Twitter data dump, sends the file to the server, which returns a "daily summary" formatted data in return.
  - Mad: or, something that takes authorization tokens, and potentially existing data, and returns the new/complete/merged data.
- Bastian: I'd been imagining just the "library for data operations" that is used in a notebook, that transforms data without needing to send/receive from a server
  - Mad: that's fair and it could probably be used that way, but it would end up being language specific, which is limiting -- e.g. only Python, and not available to R or JavaScript
- Mike: concrete example - would like to make a GET request to Open Humans API for "number of steps per day" and it returns this from an endpoint, or "sleep duration" measurements
  - Mad: there's an issue with different sources, how would that be handled; Mike: returning all sources separately, attaching source name to each.
  - Vincenzo: Apple Health integrates these too
- D G: if people haven't tried using "personal notebooks" -- should try that
- Bastian: the Apple approach is "nicely broken down" into these properties...
- Mad: I don't have an issue with Open mHealth format per se, just that I didn't have any easy way to implement it -- the proposal above might indeed produce data formatted in that way
  - Mad: the goal probably also includes operations that can be done on the standard format
- Mad: copying/sharing from Gary examples of what data analysis issues people run into:
  - Collation questions, such as:
    - Are there duplicate observations in this record?
      - This should be prevented by having a unique index in the measurements table that prevents duplicate measurements for the same variable and time
    - Are all the entries in the expected order?
      - Mike: We can sort with a sort query parameter in the GET request: <https://github.com/mikepsinn/open-humans-standardized-api/blob/main/open-api-v3.yml#L7529>
  - Selection and binning questions such as:
    - What are the total of # observations per day/hour/minute etc. for some window of time?
      - I keep statistics like this in a "variables" table: <https://github.com/mikepsinn/open-humans-standardized-api/blob/main/open-api-v3.yml#L7419>
    - How do I keep observations overnight in the same bin, instead of having them split at midnight?
    - How do I explore the data by dynamically changing the selection window and bin size?
      - A grouping width can be provided in seconds with get request: <https://github.com/mikepsinn/open-humans-standardized-api/blob/main/open-api-v3.yml#L7334>
  - Calculation arrangement/presentation question such as:
    - How do I view a moving average?
    - Identify periods of rapid change?
    - See the date of a minimum or maximum measurement.
      - One could use "value" as the sort param in: <https://github.com/mikepsinn/open-humans-standardized-api/blob/main/open-api-v3.yml#L7529>



- Recalculate with specific measurements removed?
  - One can filter out erroneous measurements with a minimumAllowedValue or maximumAllowedValue setting for variables: <https://github.com/mikepsinn/open-humans-standardized-api/blob/main/open-api-v3.yml#L5965>
  - One can restrict the data used to a particular time range with an experimentStartTime and experimentEndTime setting: <https://github.com/mikepsinn/open-humans-standardized-api/blob/main/open-api-v3.yml#L5824>
- Dave: It reminds me of the separation between "event databases" that record the events data in clinical/insurance data, and a separate "reporting database" that has analyzed the event data.
- Dave (and others have noted earlier): also note the importance of versioning, that the format version is likely to change
- D G: I wonder about sending a chunk/subset of e.g. accelerometer data, not the whole dataset
- Mad: concrete examples, e.g. in this notes doc? [https://docs.google.com/document/d/1xYWDpzc9s3ZHqiL-L7WBdnajw\\_664hDc9vwOeMXZqYc/edit#](https://docs.google.com/document/d/1xYWDpzc9s3ZHqiL-L7WBdnajw_664hDc9vwOeMXZqYc/edit#)
- Tech meetup: Wednesdays at 9:30am PDT / 6:30 pm CEST
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# May 27 (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: <https://tinyurl.com/y5ztlnvh>

## Attendees:

- James\*
- Mad\*
- Gary\*
- David\*
- Steven\*
- Joyce\*
- Enric\*
- Kate\*
- Richard\*
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## Topics:

- James - reflecting on hayfever
- Mad - update re impossible burger
- Joyce - could say more about EEG
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## Notes:

- James - feeling really skeptical of trying to track, unable to get the resolution I need, what I want is to solve my hayfever problem. I think I get more out of spending time doing reflection.
  - goal is to go without meds
  - started like last year with 1-5 scales and symptoms, but felt "this can't seem to capture the nuance"
    - instead, really interested in mindfulness about what I'm experiencing
    - looking at breathing techniques, from spiritual to wellbeing scientific research
      - but with these, they seem to claim a long time lag (months)
    - leading me to wonder about brain metrics, EEG
  - Joyce: I've heard a lot about the 4-7-8 method, haven't looked much into techniques involving rapid breathing
    - oral allergy syndrome - food allergy related to cross-reaction to food/pollen, flare up during the pollen season...
    - I wonder if you might consider whether there's an interaction between food triggering allergy symptoms. I don't know if anyone has studied this direction (pollen allergy affected by food)
  - Gary: I'd like to hear more about the benefit you got from the reflective part of what you're doing
    - James: regarding breathing, there's also a technique called shallow breathing, which affects histamine ... but I ruled this out, when I'm out I'm often being active.
    - on reflection: it feels I need a scale or resolution I can't get from an icon or a scale. and I think it got me thinking about what to do to make progress, to set up an intervention

- Gary: do you feel the qualitative process feels more accurate because of the time resolution? because your mind is faster?
- James: more in the moment of the symptoms, rather than "I'll reflect on this at lunchtime". taking time out to reflect on what I was feeling.
- Joyce: with CFS, it felt really important for me to take some notes. I'd think about it a lot, and it's tough because you come up with like 10 different ideas, but I'd write them all down. When I did have numbers, they could help with me testing a hypothesis. I agree that writing it right in the moment is important.
- Joyce: then the problem of super detailed notes - how do I use them? it's tough to go through them and make much sense of them.
- James: the environment and context is too complex, it feels impossible to track everything
- Gary: I'm interested in this because one of the difficult things with personal science is finding the "phenomenon" they're trying to change, how to track it. But there's situations where the "tracking" isn't capturing it, reflection seems to work better. And reflection can help create new ideas.
  - Gary: I do notice my seasonal allergies seem to be triggered by meals ... through self observation
  - Joyce: have you heard of postprandial rhinitis? a similar reaction to food
- Enric: I wonder if there's some way to classify, maybe related to the breathing techniques, see themes as you reflect. I notice in my project as I've done more notes, I notice themes and general categories emerge.
- Richard: a lot of these conversations about data collection are abstract -- it would be great to have a concrete example of why collecting the data was worth it
  - e.g. let's speculate we had all the data, what if I found that "every time I eat honey, my allergy are worse" -- or "every time I have red wine, I'll have a migraine in the next two days"
    - something non-obvious and actionable
  - ... but maybe there aren't any examples like that. If something is obvious, it's obvious. Maybe what we're talking about here is mindfulness.
  - Steven: I think our brains are amazing pattern matching machines; the technique is putting information in front of you such that the patterns can be found
  - Gary: I've seen discoveries like that - non-obvious and actionable, for the individual. But they don't have the charisma of a scientific discovery, they aren't new general knowledge that changes "science".
    - with blood testers, noticing people changed risk category over day; wasn't a surprise to clinicians
    - or maggie noticing luteal phase very short, spotting; looked at literature, and found this was associated with a nutritional deficiency. Was able to take this nutrient and it went away.
  - Richard: the main advantage a doctor has over you, is they've seen many many people. One of the hopes I have the personal science movement, is that somehow among ourselves, we can emulate that.
- Mad - reporting I tested and am NOT allergic to Impossible Burger
  - suspected FPIES <https://www.fpies.org/adult-fpies/>
  - did a food challenge and took notes: <https://docs.google.com/document/d/1YLIrGpZsZsApPDPVFyyBvYxHRmNj4jM4TCevGZ2bCc/edit>
  - Joyce: sometimes context like another food or medication in the preceding day
  - Steven: I like the document, you took as much information as you needed, noted things as you noticed them, didn't worry about having too much structure

- Gary: what did you get out of the document?
  - Mad: at first I wanted to "prove something", but then it became being honest with being wrong. One thing I learned about this was that I do have a strong capacity to imagine potential symptoms (or maybe induce via emotional state) - like skin tingling, feeling flushed and sweaty.

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- Aside re EEG from James:

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## May 20 (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: <https://tinyurl.com/y5ztlnvh>

Attendees:

- Bastian\*
- Dave\*
- Kate\*
- AJ
- Shelbey\*
- Joyce\*
- Steven\*
- James\*
- Enric\*
- Vytenis\*
- Dm\*
- Richard

Topics:

- Steven: Update/autopsy of cheat day experiment
- Anne:
- 

Notes:

- Anne: <https://f1000research.com/posters/1097570>
  - Developed heuristic that let's people solve eczema over period of 2 months
  - Worked with people to reproduce heuristic on their own cases,
  - Generally acknowledged that eczema is due to environmental factors
  - Limitations of double blind RCTs: more interested in collecting data than solving the outcome for individual
  - Can be scientific & rigorous with single-subject research,

- Steven:
  - Tried to implement cheat day framework for distractions (ban 6 days a week, allow on the 7th)
  - Framework didn't work as planned, maybe because starting at too high a level (e.g. blocked 6 days instead of starting with fewer days/alternating days)
  - Alternating days seems to work, as 'cheat day' isn't too far way
  - Blocked & unblocked days don't seem to be different
  - Enric: Freedom for blocking seems to only work on the computer, how are you managing mobile phones/tablets?
    - Steven: Using Screentime in iOS for that, having different 4 digit codes to encrypt 'password'
  - Bastian: you mentioned trying to increment it slowly, would that only be number of times a day or also different websites/tools
- Richard: Plug for QS Seattle meetup next Tuesday, 7pm Pacific time, discussing vaccinations and how it impacted people's tracked variables:
  - Registration on Meetup at <https://www.meetup.com/Quantified-Self-Seattle/events/278053618>
  - Will be on Zoom
  - So far people look in HRV, RHR, temperature
- Mad:
  - Will be trying weekly/daily symptom tracking for ADHD with Likert scale items:
    - Suggested list of 18 items to track, will check which ones are most interesting

# May 18 (Tech meetup)

9:30 PDT / 12:30 EDT / 17:30 BST / 18:30 CEST

*Note: the "tech meetup" may become a recurring meeting, but so far we're just trying it out.*

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

Attendees:

- Mad
- Vytenis
- Mike
- Bastian

Agenda:

- Mad updates:
  - made blogpost
  - did not look at github issues yet, did not research mediawiki vs django-wiki
- things to work on
  - 23andme is unhappy about branding issues with: <https://23andme.openhumans.org/>
    - Can't shut it down just yet as some activities still use this and actively request people to use it (e.g. genetics of personality type)
    - TODO Mad - make an update that makes language clear about lack of affiliation (without entirely dropping mention of 23andMe) and replaces "logo" with generic DNA image
  - also TODOs from last week (above)
- Mike: one thing I'm interested in is impact of medication and/or diet on symptoms.
  - Curious about making a myfitnesspal integration... wondering if it's "worth" it, concerned about how hard it is to get their API key
  - Mike: I've applied for an API key, and my contact at AllofUs has applied, haven't heard
  - Data export via file ... still seems limited to Premium:
    - <https://support.myfitnesspal.com/hc/en-us/articles/360032273352-Data-Export-FAQs>
- Mike: curious about fund-raising, interested in seeking funds for open source
  - Mad: funding open source has moved towards funding projects already developed and popular (a dependency for others), e.g. CZI has this perspective
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# May 13 (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: <https://tinyurl.com/y5ztlnvh>

Attendees:

- Mad\*
- Joyce\*
- Kat\*
- Enric\*
- T.A. McCann\*
- Abhik\*
- Dm
- James\*
- Shelbey\*
- Gary\*
- Bastian\*
- Dave Blackwell\*

Topics:

- Mad: brief update about projects I briefly discussed
- Gary: a couple slides I could present, 7-8 minutes, WIP (could wait another week)
- Joyce: could talk a bit about preliminary observations using Muse that Abhik told me about
- Enric: ongoing work on dream journal, could share a second intervention
- James: got a new wearable I could share briefly
- 
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Notes:

- Gary - arrhythmia long term tracking project using one button
  - aside / hypothesis: there are "bad days" where there's a lot of arrhythmias overnight, and not tracked by the one button
  - recently changed meds, very similar but previous (succinate, 2x day) was slow-acting, and new one is fast-acting (tartrate, in response to symptoms)
  - Two periods: dec 31 to apr 10 vs. apr 10 to May 13
  - on average, new medication is worse. But just looking at the data visually, it's not clearly worse -- very random. "worse"?
    - Brings up what "worse" means? It'd be expected that if you only take it when you need it (on "bad days"), you'll have more mild episodes... and maybe more episodes overall.
    - Also there's a couple days I forgot to bring my meds with me, and would've taken them if I'd had them ... if I remove these and it accounts for the changes, I plan to continue with the new med. If not... not sure how to think about this.
  - Dave: what was the concern with the med?
    - Gary: had some concerns about overnight effects. heartrate was unusually low for me.
    - Dave: for me it really impacted my ability to think clearly
    - Gary: I'm sure it affects people differently... for me, distractions are a problem, maybe the drug even helps
  - Abhik: how do you track when you take the medication?
    - Gary: I'm just writing it down in a text document (date and time, sometimes brief notes)... I noticed a pattern where I'd be reminded to take the drug due to arrhythmias. Unclear how... (am I psychologically prompting it, unconsciously?)



- Gary: then when switched to ad libidum, more extensive notes about why I took it.
- Enric: question about notes - what app? Gary: Apple Notes
- Gary: reflecting on the whole course of tracking arrhythmias, pre-medication it was lower, then nearly disappeared -- then when way up in October 2020, triggering starting medication. Since medication it's "gotten better" but still not as low as when I started in 2020.
  - There's also what feels like a rhythmicity, like... monthly. I suspect there's a self-reinforcing pattern, arrhythmias increase future arrhythmias.
- Dave: have I gotten you interested in getting genomic data?
  - Gary: no -- part of it is that I'm already at my limit on information with this project
- Joyce - had some preliminary use of the Muse S
  - I've heard CFS has intrusion of daytime associated waves during sleep (alpha?) ... and intrusion of sleep waves (delta?) during the daytime. That would seem to fit.
  - Haven't looked at nighttime. Abhik recommended another app, MindMonitor, but haven't seen much from overnight. And don't meditate (so I'm not using it for that purpose)
  - Interested in effects of food; I'm concerned about hidden food sensitivities, which can have delayed effects.
  - Noticed that when waves are good and feeling alert, gamma waves (associated with learning and cognitive ability) are higher ... and a tendency after a meal for these to be lower. True for beta waves as well.
  - Mad: I'm curious if you've had any surprises, learned anything new? e.g. a food you expected to have an effect and it didn't, or one you thought wouldn't but did
    - Joyce: no, and wondering to what extent it's something I influence, I've heard of "training" brain waves
  - Abhik: I'm curious what tools you're using
    - Joyce: had trouble using the mindmonitor tool, emailed developer and still difficult. I've been using a "graph in Excel" approach that's made it much easier
    - Otherwise, looking at the data and jotting notes about what it looks like
    - Planning to switch to using the Muse S app to see what I learn from that
    - Aside: I've seen someone comparing oura vs muse S said Oura underestimated deep sleep and overestimated waking
    - Abhik: if I come up with some pipelines for the data analysis, I can share those and also example data that might help contextualize your own data
  - AJ: regarding the concern about whether measurements are due to expectation / placebo effect (which is a common concern in self research) -- I wrote a blog article a couple years ago. But to recap, a group of researchers looked at all clinical trials since placebo effect became a concern where there was intervention vs. placebo vs. "nothing"
    - and looking at placebo vs. "nothing" they found no significant clinical "placebo effect", in terms of long term physiological impact
    - in asthma patients, there was a placebo effect in how they reported things, but not in physiological data -- impacts perceptions. (so, may impact "pain" which is a perception, but seems to not affect "hard data")
    - blog post on the topic: <https://solveeczema.org/eczemablog/?p=1059>
- Enric - sharing a new intervention in dream journaling project
  - using one-button to try to track "smartphone dependence" ... playing with duration too. Click when I have an urge to use smartphone, longer click = stronger urge to use the smartphone.
  - Making observations in a diary with timestamps. Trying to match observations against what's recorded in the diary
  - sketched the visualization I wish I could have... combining data over time, duration of presses, and mouse-over to see observations ... but haven't seen a visualization tool that would do this for me

- questions: (1) distribution over the daily period (2) positive vs negative impulses over time (3) how observations relate to smartphone impulses ... main question is how I might achieve this visualization?
- Mad: what's positive vs negative about? and have you started collecting this impulse data, how long, any insights on the data collection experience?
  - Enric: sometimes it makes sense to be using the smartphone (positive), but sometimes impractical when I shouldn't be doing so (negative)
  - Gary: so when it's a positive phone impulse, a short click? Enric: right, it's a quick click, and when there's more significant moments I make a long click and also try to write up notes about it (so longer press indicates there should be an annotation that will be associated with it)
  - Gary: do you want to do this yourself? or work with someone else? Enric: I can't do it myself
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## May 12 (Tech meetup)

9:30 PDT / 12:30 EDT / 17:30 BST / 18:30 CEST

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

Attendees:

- Vytenis
- Mike Sinn
- Mad Ball
- Bastian Greshake Tzovaras
- Luca

Agenda:

- What is our goal for a tech meetup?
- Updates on tech things
- Tech todos
- Data simplification tool
  - Mad's notes/thoughts on this: [https://docs.google.com/document/d/1xYWDpzc9s3ZHqiL-L7WBdnajw\\_664hDc9vwOeMXZqYc/edit#](https://docs.google.com/document/d/1xYWDpzc9s3ZHqiL-L7WBdnajw_664hDc9vwOeMXZqYc/edit#)
  - I added a "Purpose" section as a "suggestion" to try to help focus on the features that are essential for achieving the most common human goals rather than trying to handle every data type and case in the world
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Notes:

- Go around - what are we hoping to get out of tech meetups?
  - Mad: for me, to structure the process of doing tech/coding work with Open Humans. I've been out of it for a year over the pandemic, and getting back into it -- in the past this routine

was mostly one on one with Bastian (prioritizing things to work on, updates) and it's been hard to restart that, but this tech meetup could work this way

- Mike: Wanting a global, anonymous health data bank
  - Luca: what's the mission or goal behind quantimodo?
  - Mike: developed quantimodo after struggling with personal health issues, identifying dietary factors that dramatically helped me. generally motivated to want to reduce suffering and make the world better & a nonprofit
  - Mad: any more specific tech goal for this meeting?
  - Mike: the temporal data matters, and focused on the specific end of determining what "factors" affect an outcome of interest for an individual, so they can potentially make lifestyle changes to change that.
    - A functional consequence of this is that you don't need higher frequency of "predictor" data than the "outcome" data it's affecting. So resolution issues might create complexity and "weeds".
- Bastian: ditto Mad, seeing what OH should focus on developing next, so having an open meeting discussing these things is valuable
- Vytenis: interested in data simplification
- Luca: would like more discussion of what a data simplification tool, desires there, is needed at this stage. A hackathon could be great. Not sure what the goals of Open Humans are.
  - Mad:
    - OH shouldn't be me or Bastian, but rather the people + platform.
    - With that caveat what I think OH should be doing: Not wrong that historically the focus was on helping people to contribute to (academic) research. But we learned that researchers aren't super interested in this.
    - more generally we are interested in how to democratize data use for both individuals as well as groups (e.g. patient-groups).
    - Informed by other peer-production things like wikipedia, open source, etc.
- Contributing to Open Humans code
  - Mike: I noticed a few different initial setup readmes... all the python repositories, can they all have the same setup readme? Each of them uses their own database? All the different data sources have their own repository.
    - I tried the Spotify one randomly. There's a readme, and there's a main website readme that's different. It's a pain to set up the databases locally -- can there be a deploy to heroku button in these? Then it'd be easy to run it there.
  - Mad: noting that there's a distinction between all the "activity" repositories, which are modular and interact with Open Humans via the APIs.
    - We've written these in Python/Django because that's what we were familiar with -- but can be any language.
    - The main site is Python/Django and much harder to develop.
  - Bastian: would be nice to have universal readmes but unfortunately they got tweaked and modified and are all slightly different... deploy to heroku is possible
  - Mad: an aside on helping converge on instructions/help -- I've been talking a lot about trying to add a wiki for Open Humans
  - Bastian: what I'd like is to have a comment/talk page for every page on Open Humans... which wouldn't be possible with a MediaWiki
    - Mike: another idea is to add Disqus comments to activities as a "talk"
  - TODO for Mad: to do more research into mediawiki vs integrated django-wiki, pros and cons for these approaches
- 
- The file uploader (upload.openhumans.org) is now "approved" and visible on OH

- Mad: this means files can be uploaded and tagged with a "data type" and the next "use case" is being able to filter on this e.g. in notebooks ... so maybe adding the ability to search for notebooks according to data type, rather than data source.
- Mad: should this go as a featured projects? should these be updated? these haven't been updated since before the pandemic. yeah, it's hard coded
- Luca: the news posts are dated, that sucks
  - Mad: fair point. TODO for Mad, post on the blog an update about the file uploader.
- Data standardization
  - Luca: is the goal to not standardize the data stored in Open Humans, but convert to something standardized
    - Bastian: yeah, to simplify using it
  - Abhik: I'm interested in the multiformats approach mostly used in the P2P decentralization space, which is a self
- Mad: want to recognize Vytenis's question about "is there a roadmap" -- another TODO for me is to clean off the GitHub issues
- Bastian: I'm interested in improving the usability, user experience of using notebooks in Open Humans
  - Luca: would this be after data simplification, or before that?
  - Bastian: I think this goes hand in hand, as the data simplification is needed to
- Luca: what are the next steps for the data simplification tool?
  - Mad: I think we need to have a series of use cases to see the what the shared pain points are
  - Luca: how ready are we to try to do a "data standardization" thing?
  - Mad: I think there's too little specificity
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## May 06 (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: <https://tinyurl.com/y5ztlnvh>

Attendees:

- Mad Ball\*
- Bastian Greshake Tzovaras \*
- James\*
- Vytenis\*
- Luca\*
- Kate\*
- David Blackwell\* <https://my.pgp-hms.org/profile/huFE0257> Atrial Fibrillation, Eliquis, CPAP, B12, D3, Zinc, B1 Thiamine, TAVR, Kardia EKG device, and blood pressure tracking. Primary Biliary Cholangist
- Mike\*
- Enric\*
- Abhik\*
- Joyce
- Add your name

## Topics:

- Mad: Small update on last week's project
- Luca: Two small things: Question about microbiome analysis and new app that he's exploring
- 

## Notes:

- Luca - two topics
  - one is related to stomach issues for a couple years, trying to figure it out, wondering about dysbiosis
    - looking at mymicrozoo - was the only one I found in EU that did sequencing and not just culture ... if there's any suggestions, happy to hear others (I know there's others in the US) <https://www.mymicrozoo.com/en/>
    - Mike: I did viome ... it did not give specific strain breakdown, instead stuff like "looks at certain pathways" and tells if there's healthy biomarkers
    - Luca: hope is to know the specific dysbiosis to target it more effectively, with antibiotics or probiotics
    - Bastian: caveat that this type of data can vary a lot, even the same sample, sampled twice, can have two very different distributions of species
    - maybe the thing to focus on is the presence of "bad bacteria" or tracking functional things like symptoms
    - Bastian: Even diversity of bacteria isn't necessarily relevant: <https://www.nature.com/articles/ismej2016118>
  - other thing was a new app I've been trying
    - Bearable.app: <https://bearable.app/>
    - tracking symptoms.
    - all manual, UI is nice. can export to CSV. I'm using it to track 15 symptoms... energy levels, diet.
    - Mike: for getting this data into OH, how would I go about it?
      - <https://www.openhumans.org/activity/data-uploader/>
      - ^^^ activity to upload "any data file"
      - And add data types marked as "uploadable"
      - <https://www.openhumans.org/data-management/datatypes/>
      - ^^^ Mad: I should finish the upload.openhumans.org app
- Mad: Talked about ADD evaluation last week and brainstormed how to track whether medication works
  - Diagnosis was done through online test, similar to stroop task
  - Idea brainstormed last week was using Puck.js one-button tracker to record when refocusing happens
    - open question: how can we detect "am I using it?" motion?
      - Bastian: maybe record temperature, and can infer because it should be warmer due to body heat. the motion detection might consume the memory.
    - 
    - Richard: Did you check out the reporter app? <http://reporter-app.com/>
      - Mad: Yes, I remember looking at it... I've been using imoodjournal
      - Mike: <https://moodmap.app> - This allows you to
        - Designed by someone with ADD
        - testing working memory by remembering a sequence of numbers
  - One other self experiment topic, very classic self-experimentation
    - Two incidents of gastric pain & vomiting after eating food (about 3 hours), trying to figure what it might be

- Hypothesis: Found a potential food that causes it, Impossible Food burger
  - Tried for a 3rd time yesterday, and got some symptoms but not as badly as the times before.
  - Vegan burger that has a GMO leghemoglobin in it to give a meat taste
- So... next step maybe ... trying to get some isolated amount of this hemoglobin
- symptoms felt like this, rather than a food intolerance  
<https://www.fpies.org/adult-fpies/>
- Bastian:
  - Found the paper Impossible Foods for FDAL:  
<https://journals.sagepub.com/doi/10.1177/1091581818766318>
  - Can maybe order Leghemoglobin online:  
<https://www.mybiosource.com/recombinant-protein/leghemoglobin-a/1082889>
    - Here's the actual Glycine max one:  
<https://www.mybiosource.com/recombinant-protein/leghemoglobin-a-lba/1076489>

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# May 04 (Community Call)

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: <https://tinyurl.com/y5ztlnvh>

## Attendees:

- Mad Ball\*
- Mike Sinn \*
- Dave Blackwell\*
- Vytenis Darulis\*
- Sowmya Rajan\*
- Lotty Coupat\*
- Richard Sprague\*
- Bastian Greshake Tzovaras \*
- Paula Leonova\*

## Topics:

- Software library for cleaning & standardizing self-tracking data?
- Examples:
  - HPI personal data tool: <https://github.com/karlicoss/HPI#readme>
  - Quantimodo
    - [API Docs](#)
    - [Example Schema](#)
    - Measurement Properties
      - Value
      - Unit (i.e. bpm, One to Five Rating, etc.)
      - Timestamp
      - Variable Name (or ID)
      - Unit Name (or ID)
      - Duration
    - Variable Categories: <https://docs.quantimo.do/#/variables/getVariableCategories>
- Objectives:
  - Determine the effects of controllable variables on outcomes of interest
    - [Outcome Labels](#)
    - [Predictor Outcome Studies](#)

## Notes:

- (see [Slack Thread](#) in the #one-button channel) Frustration about how hard it is to get data out from different devices, OH is great at solving that step, but then the data is still in lots of different formats and needs to be converted into a shared format to visualize/merge the data
- Mad: should we decide to focus this on "time series" data
  - So not genome, or birthdate, other "permanent data"
  - Microbiome data \*is\* a form of time series data
- Richard: I'd love some unifying schema that "everyone" decides on -- ideally hand all data over to a place or tool, it turns it into a common data format, and I can use that
- Mad: what are some use cases, if you had this "universal data format"

- | Data Type | Start Time  | End Time    | Unit      | Software Ver. | Software OS | Software OS Amounts   |
|-----------|-------------|-------------|-----------|---------------|-------------|---|
| HEARTRATE | 2021-05-02T | 2021-05-02T | BEATSPERM | 1.0.6875H     | ios         | 14.5 71.0, 72.0, 72.0, 71.0, 69.0, 70.0   |
| HEARTRATE | 2021-05-02T | 2021-05-02T | BEATSPERM | 1.0.6875H     | ios         | 14.5 103.0, 99.0, 92.0, 85.0, 81.0, 77.0, 73.0, 76.0, 76.0, 78.0, 87.0, 96.0, 94.0, 89.0, 85.0, 89.0, 89.0  |
| HEARTRATE | 2021-05-02T | 2021-05-02T | BEATSPERM | 1.0.6875H     | ios         | 14.5 84.0, 81.0, 85.0, 91.0, 94.0, 92.0, 91.0, 91.0, 85.0, 87.0, 84.0, 84.0, 84.0, 87.0, 84.0, 83.0, 93.0   |
| HEARTRATE | 2021-05-02T | 2021-05-02T | BEATSPERM | 1.0.6875H     | ios         | 14.5 83.0, 79.0, 78.0, 78.0, 80.0, 81.0, 85.0, 95.0, 96.0, 97.0, 97.0, 99.0, 96.0, 97.0, 100.0, 102.0, 10.0 |
| HEARTRATE | 2021-05-02T | 2021-05-02T | BEATSPERM | 1.0.6875H     | ios         | 14.5 60.0, 61.0, 57.0, 58.0, 62.0, 62.0, 61.0, 59.0, 61.0, 63.0, 72.0, 69.0, 72.0, 63.0, 60.0, 62.0, 62.0   |
| HEARTRATE | 2021-05-02T | 2021-05-02T | BEATSPERM | 1.0.6875H     | ios         | 14.5 59.0, 61.0, 67.0, 70.0, 68.0, 66.0, 70.0, 66.0, 65.0, 71.0, 71.0, 66.0, 65.0, 72.0, 68.0, 70.0, 70.0   |
| HEARTRATE | 2021-05-02T | 2021-05-02T | BEATSPERM | 1.0.6875H     | ios         | 14.5 57.0, 57.0, 56.0, 56.0, 56.0, 56.0, 56.0, 56.0, 56.0, 56.0, 56.0, 56.0, 56.0, 56.0, 56.0, 56.0         |
| HEARTRATE | 2021-05-02T | 2021-05-02T | BEATSPERM | 1.0.6875H     | ios         | 14.5 60.0, 57.0, 57.0, 58.0, 57.0, 58.0, 58.0, 56.0, 58.0, 56.0, 56.0, 56.0, 55.0, 56.0, 55.0, 56.0         |
| HEARTRATE | 2021-05-02T | 2021-05-02T | BEATSPERM | 1.0.6875H     | ios         | 14.5 60.0, 62.0, 64.0, 61.0, 58.0, 58.0, 61.0, 64.0, 65.0, 71.0, 81.0, 69.0, 61.0, 57.0, 60.0, 55.0, 56.0   |
| HEARTRATE | 2021-05-02T | 2021-05-02T | BEATSPERM | 1.0.6875H     | ios         | 14.5 60.0, 60.0, 60.0, 60.0, 60.0, 60.0, 59.0, 57.0, 60.0, 58.0, 57.0, 59.0, 60.0, 59.0, 59.0, 59.0, 59.0   |
| HEARTRATE | 2021-05-02T | 2021-05-02T | BEATSPERM | 1.0.6875H     | ios         | 14.5 58.0, 59.0, 62.0, 63.0, 63.0, 61.0, 59.0, 61.0, 62.0, 62.0, 64.0, 65.0, 67.0, 54.0, 59.0, 59.0, 61.0   |
| HEARTRATE | 2021-05-02T | 2021-05-02T | BEATSPERM | 1.0.6875H     | ios         | 14.5 61.0, 58.0, 59.0, 58.0, 60.0, 61.0, 61.0, 62.0, 62.0, 62.0, 62.0, 61.0, 63.0, 63.0, 61.0, 60.0, 61.0   |
| HEARTRATE | 2021-05-02T | 2021-05-02T | BEATSPERM | 1.0.6875H     | ios         | 14.5 59.0, 59.0, 57.0, 59.0, 61.0, 58.0, 62.0, 58.0, 57.0, 59.0, 52.0, 57.0, 60.0, 58.0, 58.0, 58.0, 59.0   |
| HEARTRATE | 2021-05-02T | 2021-05-02T | BEATSPERM | 1.0.6875H     | ios         | 14.5 57.0, 60.0, 55.0, 56.0, 55.0, 60.0, 52.0, 54.0, 58.0, 58.0, 58.0, 56.0, 59.0, 61.0, 55.0, 58.0, 62.0   |

- Paula
  - Aggregation techniques could also vary based on use cases, how granular and 'accurate' do you need the data to be. Perhaps the granularity is not possible for certain intra-device because of hardware?
  - aTimeLogger <http://www.atimelogger.com/>
- References:
  - Bastian: IIRC accuracy depends e.g. on "when you're using the device, what the context is" -- because it's context dependent (and we don't know context" that makes it hard to solve easily.
  - Bent, B., Goldstein, B.A., Kibbe, W.A. *et al.* Investigating sources of inaccuracy in wearable optical heart rate sensors. *npj Digit. Med.* **3**, 18 (2020).  
<https://doi.org/10.1038/s41746-020-0226-6>
  - Daniel M Roberts, Margeaux M Schade, Gina M Mathew, Daniel Gartenberg, Orfeu M Buxton, Detecting sleep using heart rate and motion data from multisensor consumer-grade wearables, relative to wrist actigraphy and polysomnography, *Sleep*, Volume 43, Issue 7, July 2020, zsaa045, <https://doi.org/10.1093/sleep/zsaa045>
- Mad: the one button brings up a question, there's a duration -- is it "start" + magnitude of time ... or a start and end?



- Paula: I try to record everything, start and end, and I use all of it
- Bastian: Apple Health uses "start, end, info" format, the third can be binary -- so for a one button you might encode it like this, even though it's somewhat redundant: start + end + duration.
- Luca: there's many types of data, continuous vs point sample, and the point sample can have anything -- value, boolean, text.
- Paula: I think it's possible to do a bottom up and top down approach, starting from one use case and see if it can be generalized. Luca, you mentioned five types, what were they?
  - discrete events (one-button, meal tracking, medication intake, ...)
  - discrete samples of continuous processes (mood, energy levels, etc)
    - Mad: there's "this is the temperature when I looked at the thermometer at this time" vs "this is the average temperature that was measured over the past hour, reported on an hourly basis"
  - time-limited events ("nap", "workout", ...)
  - continuous monitoring of continuous processes (heart rate, temperature, etc. - this is really a limit case of (2), since they are still discrete samples - only more of them)
- Richard: to point out, in addition to Apple ... there's other standards, e.g. the FHIR standard, it's a common issue in medical equipment -- idk to what extent people have looked into existing standards but that's another thing to consider
  - Luca: I also came across open mhealth <https://www.openmhealth.org/>
  - Bastian: I think one response I'd have for these is that ... these are generally super overkill for what people want to do with it. Similarly, the Apple Health XML file is really complex, I just want a couple columns in a CSV. What we want isn't the ideal format that captures all the info
  - Richard: something that's super lightweight that's consistent
  - Paula: the simplicity of plug and reuse is what's appealing Bastian: or think of it as a "dataframe", not necessarily CSV.
  - Luca: ultimately we want to be able to spit out a dataframe, to make plots, access it in a "frontend"
  - Bastian: not saying should store as CSV in Open Humans, but a standard accessibility tool that spits it out as a dataframe ... CSV ... standard table format
- Mad volunteered to write a manifesto that can be widely circulated :-)

# April 29 (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: <https://tinyurl.com/y5ztlnvh>

Attendees:

- Mad Ball
- David Blackwell <https://my.pgp-hms.org/profile/huFE0257> Atrial Fibrillation, Eliquis, CPAP, B12, D3, Zinc, B1 Thiamine, TAVR, Kardia EKG device, and blood pressure tracking. Primary Biliary Cholangist\*
- Dimitri\*
- Enric\*
- Bastian\*
- Shelby\*
- Gary\*
- Steven\*
- Joyce
- Richard
- Add yourself

Go-around / topics:

- Gary: discussion topic: was asked if HR jumped after COVID-19 vaccination
- Mad: can talk about self-research ideas

Notes:

- Gary: Didn't have any side-effects after the vaccination doses, but people claim there might be a raise in HR post-vaccination. Not true on personal level
  - Could ask people who use QF and see if anyone sees a RHR raise
- Mad: Sounds very doable to send people to a form to record date/time of vaccination + which vaccine they got. But then of course it's work, to try to merge that data with any other data and analyze it.
- Gary: question might be "why do it?" one might be to wonder if different vaccines have a different effect... I think unlikely we'd have enough data to figure that out.
- Joyce:
- Shelby: People's lifestyle can also change a lot post-vaccination due to people return to normal life, large confounding variable
  - e.g. going out drinking to celebrate afterwards
- Mad: If I was skeptical about if doing this project is worth it I'd wonder if the HR response is only found in people that have noticeable symptoms post-vaccination
  - So maybe the thing to do is ask about symptoms, it would be more interesting if HR changed despite mild symptoms
  - Gary: I think there's a persistent curiosity about whether HR is a good signal for "immune response" -- so an HR change in response to vaccination would support that connection
- Richard: see also Esther Dyson not finding data changes due to vaccine:  
<https://neo.life/2021/04/an-experienced-health-tracker-gets-the-covid-19-vaccine/>

- Btw, the Seattle Quantified Self group will have a virtual meetup the week of May 24 and we are probably going to focus on self-tracking during vaccination.
- Mad: Started having interest in mood tracking, following the suggestion that behaviour might be related to ADHD. Having 2 kids + a brother with ADHD.
  - One symptom for adult ADHD is emotional dysregulation which we talked about some weeks ago. Also some other incidences that would fit
  - Trying to test Methylphenidate as typical medication and track the effects, potentially also blinded
  - What could I track?
    - Gary: my first thought was 'frustration', looking for high-level concept that you could have high degree of confidence in
    - Joyce: what about "forgetting what you were doing when you walk into a room" Mad: that happens a lot to me
    - Joyce: maybe also interested in Muse, effects with that
    - Gary: consider writing down a prediction, how often do you think you'll press it?
    - Mad: and maybe it's the phenomenon of "what was I doing?" more generally, not just specific to entering a room
    - Gary: I recall the project of returning to meditation, it was easier to track "I need to return to meditation" -- it's tracking the process of needing to refocus
    - Steven: one suggestion, general statement about all projects, write down hypotheses about what's going on, how you think the phenomenon works. document where you are right now in your understanding. map out your current mental model. (this can reveal gaps, reveal potential questions to ask.)
- Gary: technical question - writing notes in my project, and times I took the notes is on the time, but when putting into spreadsheet I can't figure out what format to put the time. Some records have dates without times.
  - Richard: are you using Excel? Gary: Numbers, can try changing...
  - Dimitri: don't worry about zeros for the dates without times. if you need to you can later force/interpret the time to a regular time.
  - Bastian: I'd suggest noon at least over zero, so it's "centered" on the day. 12 instead of zero.
- 
- 

## April 22 (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: <https://tinyurl.com/y5ztlnvh>

Attendees:

- 
- Bastian Greshake Tzovaras \*
- Gary Wolf\*
- Mike Sinn\*
- Dm\*

- David Blackwell <https://my.pgp-hms.org/profile/huFE0257> Atrial Fibrillation, Eliquis, CPAP, B12, D3, Zinc, B1 Thiamine, Walking, Kardia EKG device, and blood pressure tracking. Primary Biliary Cholangist
- Steven\*
- Mad\*
- Shelby\*
- Enric\*
- Richard Sprague\*
- Abhik\*
- Katharina\*
- Kate\*
- Add yourself

Go-around / topics:

- Added during the go-around
- Mad: has a product to share & would like to invite ideas on a project
- Mike: little case study on myself to share
- Enric: Some updates on sleep & dream tracking project

Notes:

- Mad product I found:
  - Placebo pill <https://www.amazon.com/dp/B00NUKW26M/>
  - Steven: maybe of notice, Show&Tell talk about deliberate placebo pills <https://quantifiedself.com/blog/nancy-dougherty-on-mindfulness-pills/>
- Enric: project wrap up
  - lifelog dreams, activity, and mood (daily self -survey with daylio; moved to google form)
  - re dreams, wrote down as much detail as I could every morning
    - looked
    - Problems:
      - majority of dreams can not be recovered
      - Tracking too many variables
    - Drop in amount of dreams that can be remembered (as measured by amount of pages in dream diary)
      - No analogous variance in sleep quality data from Fitbit (amount of sleep, 'quality metric', duration in sleep phases)
  - Gary: Was having more dreams a goal?
    - Enric: No, but the goal was to have a more detailed record of dreams in the morning, but the number of dreams that can be recovered has dropped
  - Mad: if remembering correctly, it's true that one always dreams during sleep and that some phases (e.g. REM) is the one with more complex dreams. Typically most memory of dreams when waking up directly from REM sleep
    - Enric: yes, one recommendation i read was to read more water before sleep to make you wake up more during sleep, increase likelihood of hitting REM phase
  - Kate: I've also observed this pattern of dreams, stress levels relate to the changes. Also want to stress again that sleep stages identified by Fitbit are not accurate
    - Bastian: it might still be interesting to look at "what stage of sleep did fitbit think I was in, before I woke?" to see if there's a correlation
    - Steven: note that a tool that you don't trust can make a reasoning process difficult
  - Steven: link to QS talk about dreaming Damien Catani - Dreaming in Numbers: <https://quantifiedself.com/show-and-tell/?project=884>

- Counting number of dreams each night, over many years
- transcript of talk is available if you just want to read about it
- seasonal differences, how drinking affected it, deliberately setting goal to remember more dreams increased how many
- Gary: what's the process of noting the dream?
  - Enric: Wake up, and have next to me a notebook. Turn on the light and start recording. Now using a remarkable tablet which transcribes handwriting into digital text. In the evening logging the data in a google form, adjusting form based on observations.
  - Gary: Are you writing full sentences, or just some notes?
  - Enric: To speed up things often keywords, short sentences
  - Gary: Really interesting that you started an intervention - writing down dreams - and it may lead to a decrease. One thing I did was asking myself throughout the day 'am i dreaming?' which then made it into my dreams
- Mike: sharing project
  - various symptoms: arthritis, psoriasis, depression, back pain
  - Went to number of doctors & specialists, prescribing a lot of drugs
  - Created an app to record symptoms and import data from various devices, combine it, to figure out which factors are most strongly predictive of an overall mood
    - noticed: mood and inflammatory pain correlated, mood and sleep quality correlated
    - Naive assumption would be that sleeping badly leads to bad mood next day (sleep causal to mood)
      - but correlation strongest for sleep quality the night following mood, maybe same underlying cause
    - Hypothesis: inflammation leads to change in melatonin & also affects mood
  - From Gary: link to QS talk about reactive arthritis: <https://quantifiedself.com/show-and-tell/?project=171>
  - Mike: working for a nonprofit (<https://crowdsourcingcures.org/>) related to this, interested in people contributing e.g. using the app to collect data (<https://app.crowdsourcingcures.org/>), aggregating data to understand effects of different supplements, etc.
  - Joyce: noting zonulin may be an important aspect of gluten sensitivity
    - Mike: I've noticed effects of gluten seem to take two days to appear, then lasts about a week. I wonder if the duration it takes is the time it takes for intestinal cells to turnover, I think it's around that timescale.
  - Gary: in addition to above talk, reminded of Thomas Chistiansen's work as well with detailed investigation into causes and treatment for his allergies. But a thought: would aggregating data make it harder to detect things as it averages things out that might be different and strong (in different ways) for different people
    - Mike: ideally would stratify it, separate people according eg. to genetics. that's right that averaging everyone effect sizes will decrease
    - Gary: one approach is taking techniques of group research and split people into groups. But starting at the other end, deep & detailed understanding of an individual is clearly effective.
    - Mike: was clearly helpful for me, but at the same time it's very involved, a lot of work to collect and study this much information for a single person. I think not everyone would be able to do that, would hope that crowdsourcing would make it easier.
  - Dave: recommends [Nebula.org](https://Nebula.org) for more genome data than just 23andMe
    - If anyone wants to see any of my 260+ nebula.org genetic reports let me know and we can arrange a zoom meeting. I also have my [Livewello.com](https://Livewello.com), [nutrahacker.com](https://nutrahacker.com) and [promethease.com](https://promethease.com) reports from my 23andMe variant results.

- I am in the top percentile very high genetic predisposition for Long PR interval (Ntalla, 2020)
- <https://drive.google.com/file/d/10XC0BFEGxAGhDEjTiuOOtSkZzUy27odG/view?usp=sharing> (DCB Nebula Report)
- <https://www.nature.com/articles/s41467-020-15706-x> (Ntalla, 2020)  
which is one of three Atrial Fibrillation reports  
The other two AFib reports show only average predisposition/ susceptibility
- 
- For Example  
I am in the top percentile very high genetic predisposition for primary biliary cirrhosis.
- [Primary biliary cirrhosisDCB99 \(Mells, 2011\).pdf](#) (DCB Nebula Report)
- [Genome-wide association study identifies 12 new susceptibility loci for primary biliary cirrhosis](#)
- Genome-wide association study identifies 12 new susceptibility loci for primary biliary cirrhosis
- 
- For example - Eosinophilic granulomatosis with polyangiitis (Lyons, 2019)
- I am in the 98th percentile (top 2 percent) of people with a genetic predisposition to EGPA
- [Eosinophilic granulomatosis with polyangiitisDCB98 \(Lyons, 2019\).pdf](#) (DCB Nebula Report)
- (which over activates your immune system and causes inflammation, etc.)
- This report is based on this paper:
- [Genome-wide association study of eosinophilic granulomatosis with polyangiitis reveals genomic loci stratified by ANCA status](#) (Lyons, 2019)
- 
- While I do not have asthma, I am a mouth breather, had my tonsils out and had ear infections when I was a kid. I have digestive issues and sometimes have a problem swallowing chicken and I have had air filters and humidifiers for the last ten years and a CPAP machine this year..
- I think this EGPA will be a major issue as I age.
- 
- Bastian: Q to Gary, instead of changes to baseline, would it be more useful to have a prioritized list? e.g. "this is something that worked for N other people" someone might work through that list -- "try this because it worked for others"
- Gary: yes it seems helpful to have feedback into the group from the discovery stage, not necessarily the data aggregation stage -- what do you want to try? starting with things that worked for others

# April 15 (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: <https://tinyurl.com/y5ztlnvh>

Attendees:

- Bastian Greshake Tzovaras \*
- Mad Ball\*
- Dave Blackwell \*
- Luca\*
- Dm\*
- Shelby\*
- Enric\*
- Joyce\*
- Add yourself

Go-around / topics:

- Added during the go-around
- Mad: starting with the one-button tracking (or rather, setting up)
- Enric: nothing this week, still working on tracking dreams & sleep & maybe talk next week about it
  - aside: my one button puckjs broke, maybe used it too forcefully
- Bastian: recording sleep still on todo; maybe one button topic good to chat about
- Luca: small project to share
- Dave: getting ablation, medication for cardiac arrhythmia hasn't been working well.
- Joyce: co-hosting microbiome show on clubhouse
- Shelby: still tracking baby movements, worried transverse, looking into exercises
- Dm: small things to share later

Notes:

- Luca - related to suggested small group on one button trackers & following discussion w/ Bastian about wanting to have easier access to data
  - going to start trying a few things, in case anyone is interested
  - It's the #one-button channel on the Slack
  - Bastian: idea is to make a small python library to standardize data
  - Luca: Bastian shared a library that seems similar/useful (<https://github.com/karlicoss/HPI>)
  - Bastian: thoughts were that a modular library would be ideal, add a module for a specific type of data
  - Mad: One button warnings?
    - Enric: the button broke off of mine, not sure why
      - Bastian: one issue is the "button" element is not supposed to be over the "step"
      - Mad: oh, no, I put mine back together \*exactly\* wrong -- I think it might have come in that orientation...
    - Bastian: another thing is to make sure to download data regularly, can be corrupted or button battery runs out

- Dm: sharing this  
<https://ocw.mit.edu/courses/electrical-engineering-and-computer-science/6-s897-machine-learning-for-healthcare-spring-2019/>
  - online, can watch whenever -- 25 lectures
  - Enric: I think you shared a couple of visualizations in slack that were interesting!
    - Images: <https://en.arguman.org/everyone-should-health-track-self-quantify> & <https://raw.githubusercontent.com/ran88dom99/QS-data-flow-network-graph/master/ScreenCapOfMyQSDaDataFlow2020aftdays.PNG>
    - <https://en.arguman.org/everyone-should-health-track-self-quantify>
    - <https://github.com/ran88dom99/QS-data-flow-network-graph>
    - Mad: I think one of the interesting limitations is "deciding what to try" is a cost in itself (not just, the cost of trying) -- analysis paralysis, trying to do the research in the first place is a cost
    - Shelby: I feel like attention spans are shorter and shorter, and the patience needed to collect enough data to find something meaningful it... like people are losing patience in general
    - Mad: I think there's an important point in there about how difficult it is to sustain interest over time, rather than the amount of time/work needed per se
    - Shelby: another interesting area is some people prefer uncertainty; probably unfamiliar to this group, but avoidance is also common. e.g. with genetic sequencing, that's a big issue, many people don't want to know. Mad: E4 homozygous is a classic example.
  - related to alzheimer's discussion & genetic testing
    - Joyce: Luis Carrasco's book is on Amazon, Neurodegenerative Disease and the Human Microbiota -- a relatively easy read
    - Bastian: systematic review & meta-analysis on the impact of DTC genetic testing: <https://link.springer.com/article/10.1007/s12687-017-0310-z> -- most people to react to the information (for better or for worse)
    - Joyce: Why we get sick;, book by Nesse -- evolutionary medicine,
      - most genetic diseases are rare due to selection
      - but others may have a lot of genes with slight effects
- 
- 
- 
- Go here





# April 08 (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: <https://tinyurl.com/y5ztlnvh>

Attendees:

- Bastian Greshake Tzovaras \*
- Gary Wolf\*
- Joyce\*
- Dm\*
- Jon\*
- Shelby\*
- David Blackwell <https://my.pgp-hms.org/profile/huFE0257> Atrial Fibrillation, Eliquis, CPAP, B12, D3, Zinc, B1 Thiamine, Walking, Kardia EKG device, and blood pressure tracking. Primary Biliary Cholangist\*
- Enric
- Abhik\*
- Kate\*

Topics:

- Abhik: talking about what we want from hardware we'd make ourselves
- Joyce: have some Qs about EEG for Abhik
- Gary: assessing effects of arrhythmia medication

Notess

- Gary: one step more confidence that medication effects are variable, taking it twice a day: morning & evening. Have some well-known side-effects that are experienced.
  - Sometimes wondering if medication is the right dose or if generics have different effects
    - Common questions
  - Tracking HR with Fitbit but battery life is poor, when forgetting to charge for a day it dies and the data comes out wrong due to datetime being off
  - Have a good log of self-tracked data in diary format on medication intake and can account for that. But for fitbit it's not there
    - Kate: The Charge 4 might be better at that, will give it a try
- Joyce: heard about people comparing EEG to Oura ring, with oura underestimating deep sleep and saying that she woke up more. Would like to try one, which EEG device is good for sleep?
  - Abhik: The Muse S is designed for sleep tracking and comes with a mobile app itself and there's also the mindmonitor app

# April 06 (Community Call)

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: <https://tinyurl.com/y5ztlnvh>

Attendees:

- Bastian Greshake Tzovaras

- 

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Topics:os

- Add your topic ideas here

Notes:

They go here during the chat

# April 01 (Self-Research Chat)

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

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

Recurring calendar event: <https://tinyurl.com/y5ztlnvh>

Attendees:

- Bastian
- Mad
- Dm
- Gary
- Shelby
- Joyce
- Abhik Chowdhury
- Michael
- Add yourself

Topics (done during go-around):

- To be added during start of the meeting
- Bastian: Still interested in the snoring question but haven't done anything
- Mad: maybe some questions if we have time
- Joyce: might have some few words if we run out of topics
- Abhik: maybe some points on the ECG monitoring
- Steven: small update on cheat day experiment
- Gary: can look at observable notebook and see what might be improved
- Dimitri: I discovered urine analysis is cheap! but no news beyond that.
- 

Notes:

- Mad: have been doing some DBT (dialectic behavioral therapy, sub-type of CBT) which focuses on skills training, in particular when experiencing strong emotions. Would be good to engage in monitoring which skills work and how well engaged with them. How to capture this? Does anyone have ideas about how to do this?
  - Steven: the cheat day experiment is similar in trying to record when cheating. Using a database app to record this but doesn't work well. Now using a one-button tracker for recording the incidences. Maybe a recording like this could work
  - Mad: might give it a try, but in the moment even just pressing the button might be too hard
  - Gary: Having ~2 years of experience with using a button approach, can feel good to press the button and have a record
  - Michael: DBT has a strong mindfulness-aspect, one big part is just acknowledging the emotions that happen. Recording those might be a way to do this
  - Joyce: breathing exercises have been recommended
- Steven: trying to apply the cheatday paradigm to other, non-food related behaviours
  - Currently: only watching youtube, online shopping on fridays. Trying to record infrictions on this with one-button tracker. Question of when pressing the button? Currently when starting a new video or opening new shopping tab. Also exploring how i fill the time.
  - Adding behaviours gradually

- Bastian: are you planning more behaviours to add?
  - S: podcasts are one, as i started to listen to them particularly more during pandemic
  - Abhik: problem is that one gets creative around bypassing restrictions
- Abhik: started to get the ECG device working with Bluetooth but there might be missing data and not understanding exactly where it happens/how to identify it. But the battery life is much better
  - Gary: Can you talk a bit more about the missing data? That's a very interesting issue to me, including duplication.

-

# March 25 (Self-Research Chat)

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

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

Recurring calendar event: <https://tinyurl.com/y5ztlnvh>

## Attendees:

- Mad Ball\*
- Dimitri\*
- Joyce
- Luca\*
- Shelby\*
- Dave\*
- Richard\*
- Gary\*
- Steven\*
- Bastian (for the last 20 minutes)

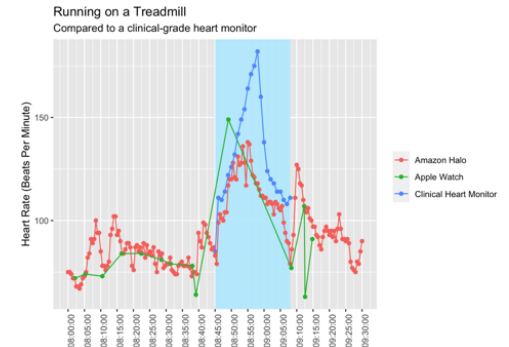
## Topics (done during go-around):

- Steven - small update on cheat days
- Richard - quick update, been playing with HRV, not getting very far but maybe folks have ideas/advice
- Joyce - new type of measurement can share if folks are interested, otherwise another time
- Gary - small idea that can share if time
- Mad - stopped self-tracking mood... nothing to share, but maybe chat about whether I should even be trying

## Notes:

- Steven - more of a lifestyle self experiment than self-tracking ... wondering if can apply "food cheat days" to e.g. "watching youtube"
  - been adding one new type of thing each week to try as "cheat days"
  - want to try to do more self-tracking, using 1 button tracker to record when I break rule (do/indulge in something when it's not on the "cheat day")
  - this past week added "online shopping" -- this has been the most difficult one yet! (more than food or youtube)
    - I think I use "planning" as a form of distraction, but it feels like work
    - used "freedom" tool to block websites to enforce non-cheat days
  - Shelby: I've tried cheat days, but found it made things worse because I'd build a desire/need to exercise the impulse during the cheat day -- encouraging binging.
    - When you do have a cheat day, are you "always doing it" or is it more that you are allowed it (but are still experiencing impulse control)
    - Steven: it feels like a reward to get it... but also get a negative feedback when I eat & makes me feel worse. At this point I'm OK with the potential for a "lost day" (eg. spent the whole day on youtube) but in the long term it's a very good question how my relationship with the indulgences changes.
  - Dave: is your goal to lose weight, focus on certain projects?

- Steven: I hope for weight loss, if it doesn't I'll have to change tactics. I think generally it's to have more of a sense of "control".
- Richard: been playing with HRV
  - losing my trust in using wearables to track stuff, would like to hear what others think...
  - tried comparing amazon halo vs apple watch vs clinical heart monitor during a treadmill test
    - clinical HR went much higher (and is presumably more accurate) while others didn't go up nearly that high
  - Joyce: I've heard that apple watch and others are generally reliable with lower HR but with exercise, not so
  - Dimitri: suggest CMS 50f uECG as more accurate during exercise
    - Richard: interesting, will check it out
- Joyce: new type of measurement that might be of interest
  - in talking to cardiologists, a lot of companies coming out with early stage stuff
  - talked to someone on clubhouse (Gustaf Kranck) interested in how breathing patterns affect vagus nerve function, monitoring using the apple watch
    - So, I've been trying this, there's a variety of measures -- producing a "vagus score" -- not the same as heartrate, been experimenting with it...
      - called "vagus ecg" (iphone)
    - he's also been working with collaborators, e.g. someone at karolinska inst studying long covid
  - tangentially meeting a lot of interesting people on clubhouse (username jcwat)
    - including someone monitoring microbes & air quality (Magnus Kolaas)
    - I tend to hang out in med tech lobby, med start group
- Gary - last week shared 1 button visualizations, and just getting started trying out the puckjs
  - wondering about maybe slack group, working group about how to use a one button, puckjs stuff, to make observations and use them
  - Mad: who do you think might be involved? how to chat would depend on who that is
  - Luca: I'm interested, is it specific to puckjs?
    - Gary: about this general type of data ... an example, Bastian created code that outputs puckjs data the same format as 1-button tracker ... but other approaches use a spreadsheet, so there's data normalization & that sort of thing is nice to discuss
    - Luca: I've been thinking about it for a while; OH is useful for inputs from existing data sources, but no standard way to input data you collect/create yourself
  - Mad: is this "event data"? if you want to get this away from calling it "1 button"
  - Gary: will make a slack channel for it
- Mad: I stopped mood tracking and I'm not sure how to feel about it (should I try to do it again? something like it? was I done?)
  - Steven: self tracking can reinforce negative self-views, like reminding yourself you're unhappy, or feeling bad about failing to do the tracking that was planned. Think about revisiting what you're motivated and interested in, in a positive way, rather than viewing it as something you need to do to address perceived problems.
- Shelby - folks with ADHD may be interested in Katri Manninen's work with ADHD self-tracking
  - <https://talk.automators.fm/t/how-i-track-my-life-with-integromat-airtable-shortcuts-and-timing-et-al/5507/20?u=kutrinet>







# March 18 (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: <https://tinyurl.com/y5ztlnvh>

Attendees:

- Bastian Greshake Tzovaras \*
- Enric\*
- David Blackwell <https://my.pgp-hms.org/profile/huFE0257> Atrial Fibrillation, Eliquis, CPAP, B12, D3, Zinc, B1 Thiamine, Walking, Kardia EKG device, and blood pressure tracking.
- Joyce\*
- Gary\*
- Steven\*
- Kate\*
- Richard Sprague\*

Topics (done during go-around):

- Bastian: Update on SpO2 idea
- Steven: Impulse control + cheat days
- Gary: Small demo of arrhythmia measurement visualization
- Joyce: small update

Notes:

- Bastian: Trying to record snoring with pillow
  - Richard: SleepSpace can also do this
  - Gary: I tried SnoreLabs too
  - Richard: Somebody recently recommended [Sleep Watch](#) if you wear an Apple Watch while sleeping.
  - Steven: talk on grinding teeth in sleep: [quantifiedself.com/show-and-tell/?project=1025](https://quantifiedself.com/show-and-tell/?project=1025)
    - Also google announced a smart display to put next to your bed that uses some kind of radar to detect movement
- Steven: Exploring if cheat days work for impulse control for things other than food/diet
- Gary: discussion of his Observablehq.com visualizations of his year-long arrhythmia tracking.  
<https://observablehq.com/@garyisaacwolf/time-series-dashboard-prototype-for-self-research-chat>
  - Looking for volunteers to make this publishable?

# March 11 (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: <https://tinyurl.com/y5ztlnvh>

Attendees:

- Bastian Greshake Tzovaras
- Abhik Chowdhury
- Luca
- Joyce
- David Blackwell <https://my.pgp-hms.org/profile/huFE0257> Atrial Fibrillation, Eliquis, CPAP, B12, D3, Zinc, B1 Thiamine, Walking, Kardia EKG device, and blood pressure tracking.
- Dm
- Shelby
- Add yourself

Topics (done during go-around):

- Add your topic ideas here
- Bastian: questions re: SpO2 measurements of Apple Watch
- Luca: one question at the end
- Joyce: one small thing
- Abhik: some feedback/discussion for Luca's project

Notes:

- Bastian: Got this blood O2 data from apple watch, i see drops during the night and wonder whether it's an issue of measurement artifacts or maybe snoring?
  - Joyce: Saw some correlation of heart rate variability with oura ring and snorelabs snore data . Also check out SnoreLabs app
  - Dave: maybe also issue of nostrils clogging up
  - Joyce: an experiment: sewing tennis balls into t-shirt to avoid sleeping on back
  - Abhik/Dm: Might well be artifacts
- Luca: Do people have some good news sources, blogs etc. about QS?
  - Dm: <https://mhealth.jmir.org>
  - Bastian: QS forums & QS sub-reddit
  - Abhik: The NeuroTechX people have a lot of stuff for neuro-things, with a Slack & Discord
- Joyce: what are experiences with food tracking?
  - Dm: Bitesnap is free and works okay
  - Bastian: <https://www.myfoodrepo.org/>, linked to <https://www.foodrepo.org/>

# March 09 (Community Call)

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: <https://tinyurl.com/y5ztlnvh>

Attendees:

- Bastian Greshake Tzovaras
- Bjorn Hansell
- Enric Senabre
- Beau Gunderson
- David Blackwell <https://my.pgp-hms.org/profile/huFE0257> Atrial Fibrillation, Eliquis, CPAP, B12, D3, Zinc, B1 Thiamine, Walking, Kardia EKG device, and blood pressure tracking.
- 

Topics:

- The Keating Memorial
- Add your topic ideas here

Notes:

- They go here during the chat
- 
- Understand the difference between probability and susceptibility
- 
- The Shallow end:
- A friendly introduction to Bayes Theorem and Hidden Markov Models by Luis Serrano
- <https://youtu.be/kqSzLo9fenk>
- <https://www.youtube.com/watch?v=kqSzLo9fenk>
- 
- [https://en.wikipedia.org/wiki/Viterbi\\_algorithm](https://en.wikipedia.org/wiki/Viterbi_algorithm)
- [https://en.wikipedia.org/wiki/Hidden\\_Markov\\_model](https://en.wikipedia.org/wiki/Hidden_Markov_model)
- [https://en.wikipedia.org/wiki/Andrew\\_Viterbi](https://en.wikipedia.org/wiki/Andrew_Viterbi) co founder of Qualcomm, successor of Claude Shannon?
- 
- The Deep end:
- IT CompBio Lecture 04 - HMMs Hidden Markov Models I (Fall'19) by Manolis Kellis
- <https://www.youtube.com/watch?v=MMYyzt3dbsg>
- <https://youtu.be/MMYyzt3dbsg>
- 
- Metabolic pathways are like Markov networks.
- <https://www.facebook.com/drbenjaminlynch/photos/pathway-planner-2-0-has/876036442425190/>
- 
- This is the music stuck in my head when thinking of Markov Modeling.
- Orkestra Obsolete play Blue Monday using 1930s instruments - BBC Arts
- <https://www.youtube.com/watch?v=cHLbaOLWjpc>

- <https://youtu.be/cHLbaOLWjpc>
- This music (and the “lyrics”) reflects my attitude toward the medical establishment.
- New Order - Blue Monday (Official Lyric Video) Lyrics - <https://www.youtube.com/watch?v=c1GxjzHm5us>
-

# March 04 (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: <https://tinyurl.com/y5ztlnvh>

Attendees:

- Bastian Greshake Tzovaras \*
- Gary Wolf\*
- Luca\*
- David Blackwell <https://my.pgp-hms.org/profile/huFE0257> Atrial Fibrillation, Eliquis, CPAP, B12, D3, Zinc, B1 Thiamine, Walking, Kardia EKG device, and blood pressure tracking. \*
- Shelby\*
- Joyce\*
- Dm\*
- Meaghan\*
- Abhik Chowdhury\*
- Paula Leonova\*
- Björn Hansell\*
- Scott\*
- Enric\*
- Add your name!

Topics:

- We'll fill in the rest during our go around
  - Gary: Can share small update on his project
  - Luca: has some slides
  - Dave: can share some reports
  - Björn: can share some productivity data
  - Abhik: some Qs re sleep data
  - Paula: can share a graph
  - Joyce: has some Qs too
  -

Notes:

- Luca:
  - Interested in sleep & energy levels
  - Setup phase: How to track things:
    - HR, workouts, sleep time & quality w/ smartwatch
    - Digital activities w/ rescuetime
    - Use NFC tags to log activities
    - How to track diet?
  - For NFC tag reading: custom sweatband with NFC reader and arduino
  - Björn: For diet tracking: what's the hypothesis you want to test? Having a clear hypothesis can make it easier to track just those parameters (e.g. not all micronutrients)
  - Joyce: Can also try elimination diet to test different foods

- Gary: Absolutely agree with Björn, we've seen lots of food tracking in QS and doing it is really hard and often fails if it's too hard. Elimination diet is also really hard, the thing that worked is 'subtraction diet' where you only remove single food at a time
- Abhik: Sometimes the vibration motors need specific driver
- Joyce: interested in breathing techniques & meditation
  - Lots of different breathing methods out there, has anyone experience with it?
    - Not really,
- Abhik:
  - Using a lot of sensors on sleep stages & heart rate
    - Agree and disagree in some ways as expected:
      - Lots of disagreement on sleep stages
    - Gary: Gold standard EEG is somewhat suspect too. Also the data they get is so noisy that they need to use multi-sensor evaluation to predict when you're probably asleep to then use more detailed data

# February 25 (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: <https://tinyurl.com/y5ztlnvh>

Attendees:

- Bastian Greshake Tzovaras \*
- Enric Senabre\*
- Dm\*
- Gary Wolf\*
- Paula Leonova\*
- David Blackwell <https://my.pgp-hms.org/profile/huFE0257> Atrial Fibrillation, Eliquis, CPAP, B12, D3, Zinc, B1 Thiamine, Walking, Kardia EKG device, and blood pressure tracking. \*
- Scott Williams \*
- Richard Sprague\*
- Shelby\*
- Katharina\*
- Abhik Chowdhury\*
- Luca\*
- Add your name!

Topics:

- We'll fill in the rest during our go around
  - Gary: Quest to better visualize data
  - Luca: has some questions
  - Joyce: some thoughts on apple watch
  - Enric/Dm: Doing a shared presentation of how to analyse data
  - Paula: Sleep schedule tracking chart
  -

Notes:

- Enric:
  - Some background:
    - Interventions for mood, sleep quality & dreams
      - How do things like reading at night, exercise, cbd, Mate 🍷 influence sleep + dreams?
    - Track with [Daylio](#), a Fitbit & qualitatively with a notebook (the old-fashioned one, not a jupyter notebook)
    - Heavily customize Daylio to cover types of dreams, sleep types, activities, social interactions, places
    - Data analyses/visualizations on Daylio very limited
  - Qs:
    - Which way are you trying to learn? From activities to sleep or vice versa?
      - It goes both ways
  - DM: showing how to use Haberman clustering

- Paula:
  - Tracking device use, sleep & activity
  - Looking at time of sleep & consistency
    - Try sleeping at 10pm, wake at 7am, also remove time being restless
    - [Chart: Wake up and bedtime goals](#)
    - [Chart: Sleep Restlessness](#)
    - Next: Try to quantify productivity and/or energy in the day
  - Bastian: correlation between morning and night
  - Abhik: sleep stages and timing it at a the right cycle
  - Gary: What is the reasoning behind your goal, maybe setting a different one since variation is low in morning and night
  - Enric: behavior changed since measuring? Paula: Yes! Keeps me accountable

## February 18 (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: <https://tinyurl.com/y5ztlnvh>

Attendees:

- Bastian Greshake Tzovaras \*
- Mad Ball \*
- Dimitri \*
- James Littlejohn \*
- Luca Roberto Giorgio Dorigo \*
- Joyce Waterhouse \*
- Katherina Kloppenborg \*
- Abhik Chowdhury \*
- Katarzyna Wac (Kate)\*
- Shelby Rolison \*
- (Meaghan)
- Omar ElNaggar \*
- David Blackwell \*
- Enric Senabre
- Add your name!

Topics:

- We'll fill in the rest during our go around
  - James Littlejohn - intro to my 2021 project  
<https://docs.google.com/presentation/d/1Sel2yF6qyPlabNqQTCutDPxfhzkKhBACnuPrOKOuD9o/edit?usp=sharing>
  - Joyce - thoughts & questions about higher tech methods for self research
  - Luca - interested in more rigorous self research, have a few questions
  - Omar - can share some details on time tracking app



- Kat - could share stuff I've put together for my project, but can also go next time
- (Dm - did some analysis of Enric's data, but he's not here, so passing this week)

#### Notes:

- Shelby - doing interviews about self research, have \$50 gift cards, sharing email in chat srolison@utexas.edu
- James - 2021 project  
<https://docs.google.com/presentation/d/1Sel2yF6qyPlabNqOTCutDPxfhzkKhBACnuPrOKOuD9o/edit?usp=sharing>
  - Last year project was tracking hayfever, via spreadsheet.
    - The plan was intermittent fasting, and I abandoned it, didn't seem wise with the pandemic. Went to standard medication.
  - Year before, was interested in kinesiology. Generally, thinking about ways to avoid needing to use the medication. Also trying Tai Chi.
  - Hoping to use these techniques & see if these help this year -- "power of mind", consciousness, as an intervention treatment for hayfever
  - James - one technical aspect I'm interested in EEG, brain wave stuff
  - Omar - have you looked at journaling or mood tracking projects?
    - James - I'm skeptical of self reporting. In the past, relied on things like air quality. The experience from last year left me frustrated with efforts at objective measures, quantitative approaches.
  - Mad - one thing Steven Jonas has tried is recording "what I expect to happen" before doing something; maybe even just writing and revisiting afterwards instead of trying to make metrics
  - Bastian - reaction time stuff Steven did may also be relevant, an attempt at objective measure
- Kat - understanding my resting heart rate along the years...
  - What I did:
    - continuous heart rate monitoring
    - heart rate, sleep, activity
    - rescue time (productivity) & google calendar
  - How I did it - devices changed over time: Basis B1 (2013-2015), Basis Peak (2015-2016), Fitbit Charge 2 (2017 - 2020), Fitbit Charge 4 (2020 - ), Oura (2020 - )
  - What I hoped to learn: checking various hypotheses, relationship between things and RHR
    - Comparing against RHR at night
    - I'm planning to look at correlations with...
      - Sleep (overall, when, quality)
      - Travel, travel sleep
      - Sickness
      - Productivity HR
      - Parties: I want to look at the difference between HR from start to end of sleep? (metabolizing alcohol / rest post party)
      - Summer, yoga, vacations, productivity quality: RHR goes down?
    - Bastian: some of these variables will be correlated with each other -- like, if you party then you'll have less sleep. How do you plan to deal with these?
      - Kat - good point, no particular plan beyond analyzing them separately
- Omar - sharing "mana", time tracking app that I've been a founder of: <https://mana.ai>
  - "mint for time", trying to manage time
    - there's an MVP live, goal setting & tracking
  - one thing I feel we've found is that journaling, reflecting on data has been important for folks

- Luca: you mentioned a lot of tracking is still manual. How much time do you spend doing the tracking if you have to do it yourself?
  - Omar - I've been spending about an hour a week doing the tracking itself.
  - We've been trying to add integrations to reduce how much manual tracking is needed. Similar to Rescue Time, but I think we have improved classifications.
- Abhik: what's the export data format look like?
  - Omar: currently I just give people database dumps if someone wants it
- one of the things we think about is the "American Time Use Survey" & reflecting that people's memory of how they spent time might not be accurate
- Mad: deliberately tracking time seems so hard to me. What are the challenges, the times you slip and aren't able to do it?
  - Omar: when I go on vacations, I often slip
  - Kat: vacations, having fun, those are times where I also slip. In vacations if there's something really significant then I do make a note
  - Abhik: aside to Kat - I'm really interested in what the 12 calendars you use, that you mentioned earlier, would love to see them when you present things in the future
  - Enric: having a routine at night has been a lot easier for me than trying to do things throughout the day
- Luca
  - Enric mentioned a one button tracker, I've been
  - Bastian: it's using Puck.js (which James introduced us to), a small open source hardware device
    - I made a small JS that you can use it, to use the device as a one button tracker
      - you can run this code in the browser to convert and use it this way: <https://tzovar.as/one-button-tracker/>
  - Luca - is there a similar bracelet wearable?
    - Bastian - yeah, Bangle.JS has heartrate, acceleratamor, etc - same idea - code/run/add apps via JS in the browser
  - Mad: Luca, did you have other questions?
  - Luca - this was one question (how to track episodes randomly). another was how to track e.g. when I'm in the shower, when I'm cooking
    - Omar: I think you'd want to look into "beacons", to track location
    - James: regarding cooking, I noticed air quality has been a
    - Bastian/Abhik: also see this blogpost from Miguel (who's also attended these meetings in the past). You might be interested in, to track what he's doing all the time at home: <https://miguelrochefort.com/blog/calendar/>
    - Integrates a variety of hardware
  - How do we integrate data from all these sources?
    - Abhik: I've been struggling and hoping
    - Bastian: the notebooks

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# February 11 (Self-Research Chat / Keating Memorial Kickoff)

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: <https://tinyurl.com/y5ztlnvh>

Attendees:

- Mad Ball
- Bastian Greshake Tzovaras \*
- [Katri Manninen](#) \*
- Enric Senabre Hidalgo \*
- Prash
- Meaghan Barry \*
- Lars Pedersen \*
- Katri \*
- Joyce Waterhouse \*
- Richard Sprague \*
- Paula Leonova \*
- Shelby Rolison \*
- Abhik Chowdhury \*
- Katarzyna Wac (Kate) \*
- David Blackwell <https://my.pgp-hms.org/profile/huFE0257> Atrial Fibrillation, Eliquis, CPAP, B12, D3, Zinc, B1 Thiamine, Walking, Kardia EKG device, and blood pressure tracking.
- Shelbi Rolison \*
- Katharina Kloppenborg
- 
- Gary Wolf
- 2021年4月9日
- Topics: battery life, reliability of observations, data access, data format, extensibility, cost, ease of use, legal and regulatory frameworks (legal to use, including by kids), support framework.

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- Open Humans Community & Self-Research Chats 2022

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- Open Humans Community Calls And Self-Research Chats - 2021

- December 16 (Self-research Chat)

- December 09 (Self-Research Chat)

- December 07 (Community Call - open / no agenda)

- December 02 (Self-Research Chat)

- November 25 (Self-Research Chat: canceled for Thanksgiving)
- November 18 (Self-Research Chat)
- November 11 (Self-Research Chat)
- November 04 (Self-Research Chat)
- November 2 (Community Call): Self Research Motivations
- October 28 (Self-Research Chat)
- October 21 (Self-Research Chat)
- October 14 (Self-Research Chat)
- October 7 (Self-Research Chat)
- October 5 (Community Call): Quantified Flu paper
- September 30 (Self-Research Chat)
- September 23 (Self-Research Chat)
- September 16 (Self-Research Chat)
- September 9 (Self-Research Chat)
- September 7 (Community Call): AutSPACES
- September 2 (Self-Research Chat)
- August 26 (Self-Research Chat)
- August 19 (Self-Research Chat)
- Keating Memorial Show&Tell Talks
- Details
- Announcement (post anywhere)
- August 5 (Self-Research Chat)
- August 3 (Community Call)

- July 29 (Self-Research Chat)
- July 28 (Tech Meetup)
- July 22 (Self-Research Chat)
- July 15 (Self-Research Chat)
- July 14 (Tech Meetup)
- July 8 (Self-Research Chat)
- July 6 (Community Call)
- July 1 (Self-Research Chat)
- June 30 (Tech Meetup)
- June 24 (Self-Research Chat)
- June 17 (Self-Research Chat)
- June 16 (Tech Meetup)
- June 10 (Self-Research Chat)
- June 3 (Self-Research Chat)
- June 1 (Community Call)
- May 27 (Self-Research Chat)
- May 20 (Self-Research Chat)
- May 18 (Tech meetup)
- May 13 (Self-Research Chat)
- May 12 (Tech meetup)
- May 06 (Self-Research Chat)
- May 04 (Community Call)
- April 29 (Self-Research Chat)

- April 22 (Self-Research Chat)
- April 15 (Self-Research Chat)
- April 08 (Self-Research Chat)
- April 06 (Community Call)
- April 01 (Self-Research Chat)
- March 25 (Self-Research Chat)
- March 18 (Self-Research Chat)
- March 11 (Self-Research Chat)
- March 09 (Community Call)
- March 04 (Self-Research Chat)
- February 25 (Self-Research Chat)
- February 18 (Self-Research Chat)
- February 11 (Self-Research Chat / Keating Memorial Kickoff)
- February 09 (Community Call)
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- Kick-off webinar for Keating Memo
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- Anatoli Babenia \*
- Miguel Rochefort \*
- Sanja (Sannya) \*
- Dm
- Anatoli Babenia
- Add your name!

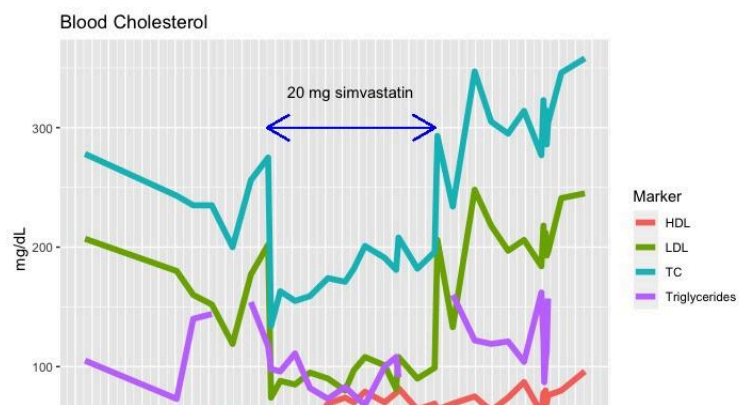
#### Topics:

- Mad Ball: Keating Memorial Kickoff
  - Slides available here:
    - [https://docs.google.com/presentation/d/1ESNOzyhH5OxZ94qv8gsUcODHWLq0R54\\_O7EB3ZK6lr4/edit?usp=sharing](https://docs.google.com/presentation/d/1ESNOzyhH5OxZ94qv8gsUcODHWLq0R54_O7EB3ZK6lr4/edit?usp=sharing)
- We'll fill in the rest during our go around
- Potential topics (go-around)
  - Bastian - can give a small update on a project later if needed

- Gary - small update with slides, maybe 6 minutes
- Enric - have something to share if needed
- Richard - working on a big project with LDL cholesterol and heart rate
- Joyce - have a story I could share about self tracking and how it helped me
- Lars - question about quantifying my cognition

#### Notes:

- Beau Gunderson: Noting before the meeting that I can't attend but do plan on participating! My question will be: "What does it mean to have a family history of prostate cancer and can my genetic data help answer that?"
  - Bastian: Super happy to chat about that! I looked into that for my dad some years back!
  - Prash: Beau, I shall be happy to discuss this hereditary form of Cancer Prostate. I am a Principal Investigator of one such project. I will be happy if we could exchange emails through [prash@Bioclues.org](mailto:prash@Bioclues.org). I will try to attend the chat. It is at 2330 hrs India time. Please excuse me otherwise.
- Mad's presentation on the Keating Memorial
  - More info about Steven: <https://news.mit.edu/2019/celebrating-curious-mind-steven-keating-0722>
- Gary - self tracking a cardiac arrhythmia
  - methods: zio patch (biomedical device), kardia home ekg (can be DIY / home use), and 1-button tracker (totti labs)
  - a question explored: is the 1-button tracker (hit when I feel skipped heartbeats) reliable when compared to a biomedical device?
    - Zio and 1-button correlated really well. On worse days they didn't correlate as well; correlation stronger ignoring these. Seems to be because many PVCs are occurring at night while asleep.
    - 1-button is cheap, Zio is expensive and has to be returned after 14 days
  - observations
    - PVCs increase throughout the day
    - 11 months of 1-button (most gaps are "real" but in December gap due to device issues)
    - Metoprolol (started in Nov) seemed to work but... I just looked at the data and it seems like I'm actually still having a lot of PVCs, more than earlier in 2020.
    - So is it really working? I think I have to try stopping it and seeing what happens.
    - Some worries about the med - unclear what the pharmacokinetics are, and there's cautions against stop/start medication. (Is that a worry?)
  - Richard: generic or brand? There's people saying generic quality is bad.
    - Gary: another test I could try is generic vs brand name. I suspect the generic works for sure sometimes -- the effects are very noticable (also heartrate drops, and some side effects) but seem very variable
  - Joyce - wonder if getting worse during the day is related to food; if you might try fasting
- Richard - should I care about my high LDL cholesterol?
  - wondering if it's related to long term changes in resting heart rate in past couple years
  - Apple watch says VO2 max has decreased a lot since last summer
  - Used to take a statin drug to control LDL & wondering whether to try it again. Stopped taking it because there's arguments that





statins aren't useful, especially if there aren't other risk factors.

- Plan: going to do a monthly blood test, tracking going back on a statin
  - Mad: are you taking a baseline?
  - Richard: yes, already collected a lot of baselines
- Bastian: did walking faster change the VO2 max? (prev noticed walking slower affects the number)
  - Richard: yes! not changed enough to return to previous levels, but it did go up immediately when I tried walking faster
- Joyce - self research story
  - in grad school was feeling sick, started with infections, went on disability. lost a lot of weight and was bedridden. this was all before chronic fatigue syndrome was a thing.
  - started experimenting with diet, gained weight but still mostly bedridden
  - medications sometimes helped but not much.
  - tried "marshall protocol", antimicrobial approaches. That was helping, but still having food reactions. Then, a dramatic decline occurring during menopause, had to abandon the marshall protocol.
  - Figured out a way on testing for food reactions, one was a variation on the pulse test (shortcut pulse test)
  - All the stuff I've learned, hoping can help others with CFS, started a company to help share this stuff
- Lars - question about quantifying cognition
  - Tried <http://www.quantified-mind.com/> which gives a variety of numbers for different tests you do. Looking for a way to quantify to test things to see if they improve cognition.
  - One thing I'm wondering about is one where peanut butter seems to make a problem worse? confusion, short term memory, brain fog.
  - looking for a tool to measure "brain fog"
  - Enric: have you tried in the past to try to track this with some tool already?
    - Lars: been tracking "focus" with a number between 1 to 5, via a prompt every 45 minutes. But later felt that this wasn't capturing everything I wanted to improve.
  - Mad: how long does that "quantified mind" tool take to do? because that prompt sounds quick and easy, so it's easy to be collecting enough data to get a feel for whether the measure is working. if you can't do it enough times, it's hard to tell if it's measuring what you want
    - Lars: about 3 to 5 minutes, not too long
  - Katri: what's "brain fog" like?
    - Lars: I lose track of what I'm thinking about
    - Sanja: have you been tested for ADHD?
    - Katri: I have ADHD and when I'm tired or affected by something like meds, it feels like this.
    - Lars: conclusion was that I have some of the symptoms, but not enough for full diagnosis.
  - Gary: I think I can help & would be good to continue this in the forum -- I've seen a lot of folks trying to get at this type of thing.
    - Gary: One thing I'd suggest is that you track the subjective experience, without worrying about trying to capture it with a special test. Try not to get caught up in the measurement and assessment -- when you have an experience that you notice, you can stick to recording that.
    - Suggestion is to start a project log, e.g. here:  
<https://forum.quantifiedself.com/c/quantified-self/project-logs/41>
  -

# February 09 (Community Call)

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: <https://tinyurl.com/y5ztlnvh>

Attendees:

- Bastian Greshake Tzovaras
- Morgan Hough
- Katarzyna Wac (Kate)
- Björn Hansell
- Abhik
- Add your name!

Topics:

- The Keating Memorial, starting this Thursday
- Quantified Flu: We're drafting a paper!

Notes:

- They go here during the chat