San Francisco July 25, 2016

Designing a Prototype
Atlas of Caregiving

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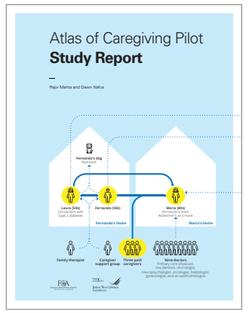
Dubberly Design Office

In 2015, Robert Wood Johnson Foundation funded a pilot study to look at new ways of measuring family caregiving.

Robert Wood Johnson Foundation

The study produced a report delivered as a PDF and website.
The report includes protocols, ethnographies, and visualizations.

Study Report



Data Visualizations

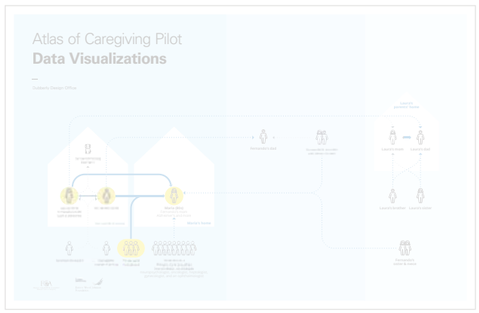
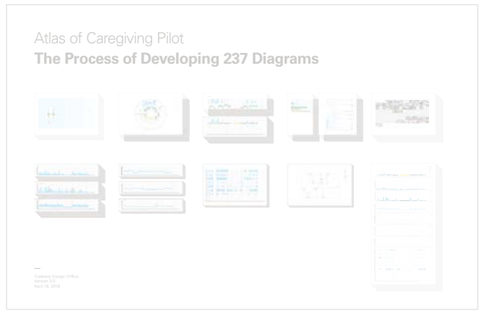
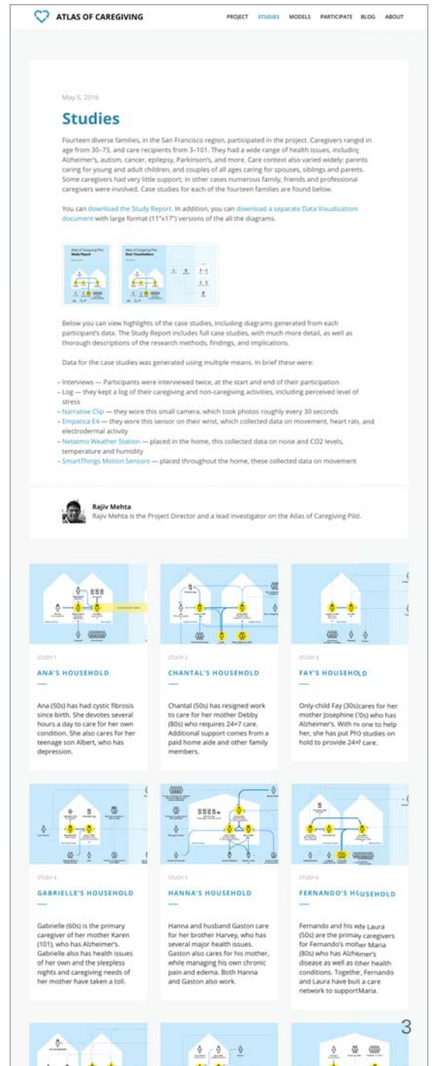


Diagram Development



Care Network Rationale

Website



This presentation describes the project:

1 **Need: Why study caregiving?**

2 **Approach: How was the study organized?**

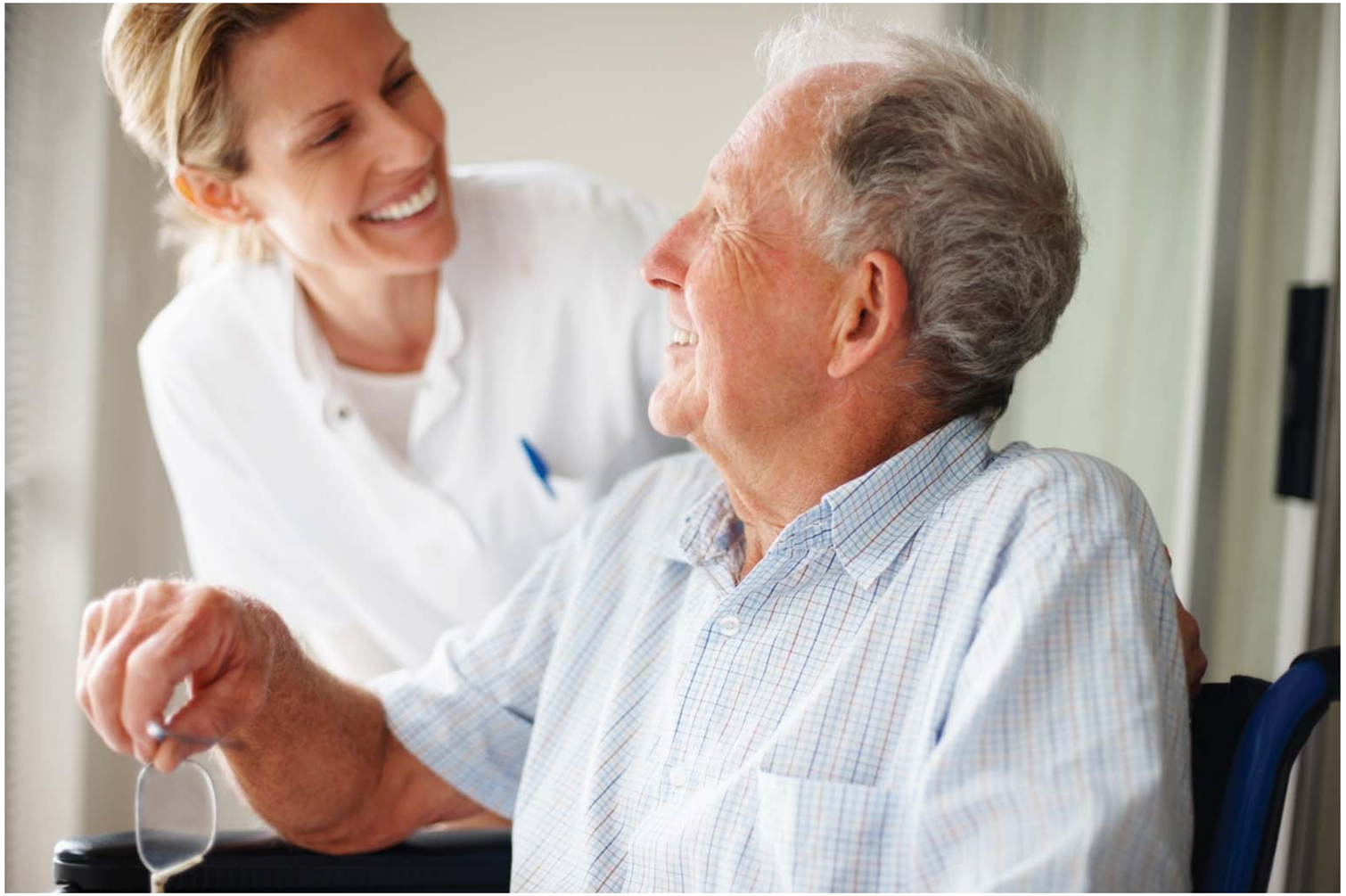
3 **Measurements: What data was collected?**

4 **Visualizations: How was the data processed?**

5 **Results: What did we learn?**

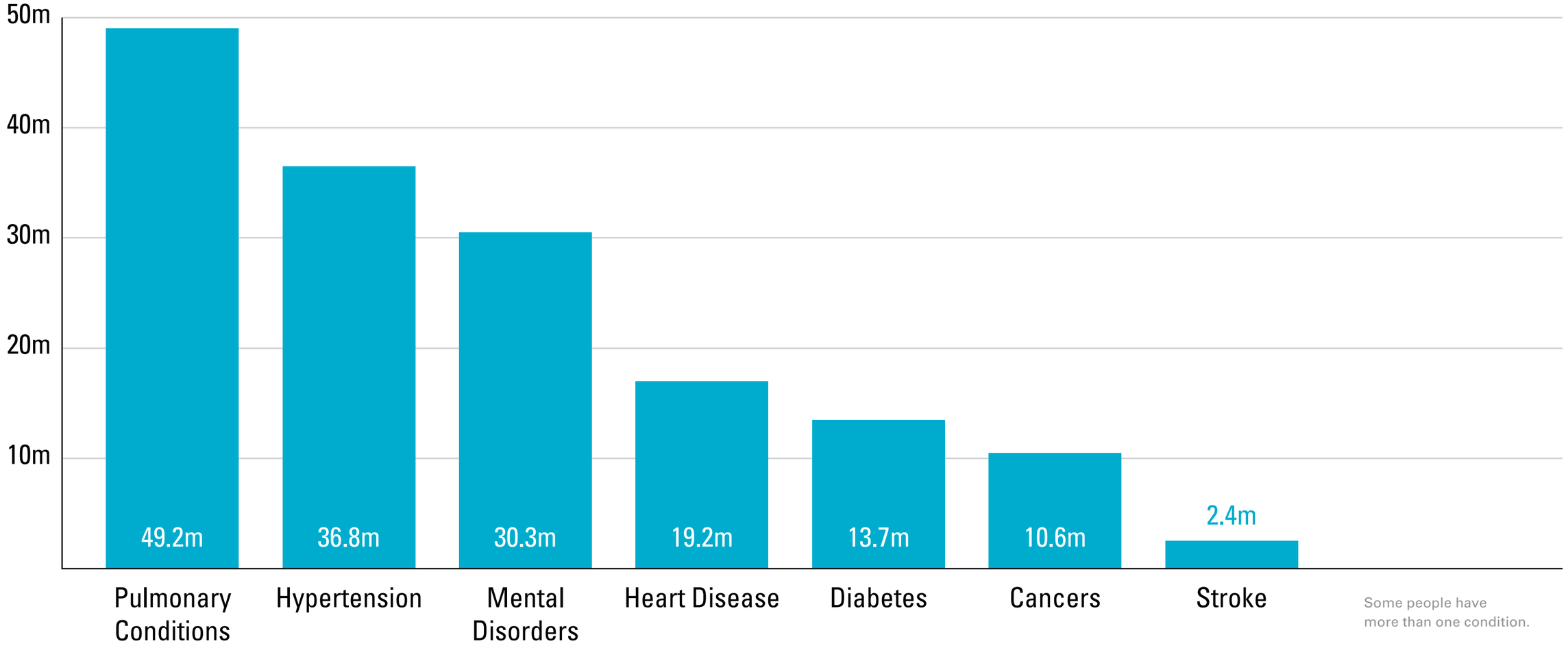
Need:
Why study caregiving?

We rely on healthcare professionals (HCPs) to help us maintain our health—typically in hospitals and clinics.



Yet many have chronic health conditions, which require self-management—and the help of family caregivers, working at home around the clock.

‘As of 2012, about half of all adults [in the U.S.]—117 million people—had one or more chronic health conditions.’



— Centers for Disease Control and Prevention (CDC)

Chronic conditions require ongoing support, often from family. Experts differ on the number of family caregivers—but it is large.

The U.S. population is ~322,000,000.
~80% are adults = ~257,000,000.
~39% are caregivers = ~100,000,000*

Source: Pew Research
http://www.pewinternet.org/2013/06/20/family-caregivers-are-wired-for-health/

Calculating the economic value (not even the social value) of family caregiving is difficult—but even the most conservative estimates are huge.

If each caregiver spends just 8 hours per week providing care, that's
8 hours / week × 52 weeks / year / caregiver = **416 hours / year / caregiver.**

If providing care is worth a minimum wage of $10 / hour, that's $10 / hour × 416 hours / year / caregiver = $4,160 / year / caregiver.

With ~100,000,000 caregivers that's
~$416,000,000,000 in unpaid labor—almost half a trillion dollars.

Traditional healthcare spending is about 3 trillion per year.

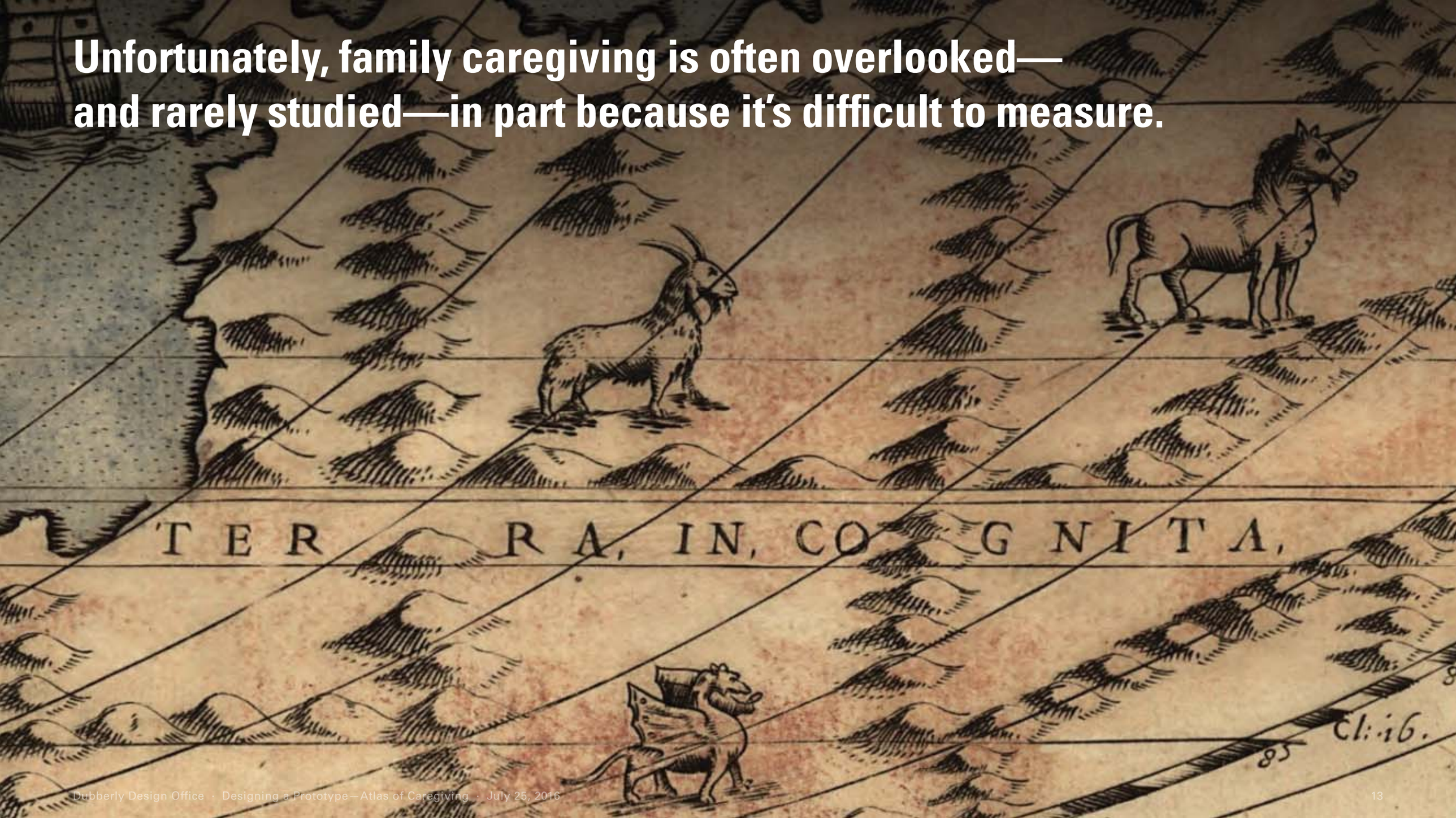
Arguably family caregiving is worth more than $10 / hour and requires more than 8 hours / week.

At $15 / hour and 40 hours / week, the hidden economic value of family caregiving approaches the economic value of the healthcare industry.

Traditional Healthcare

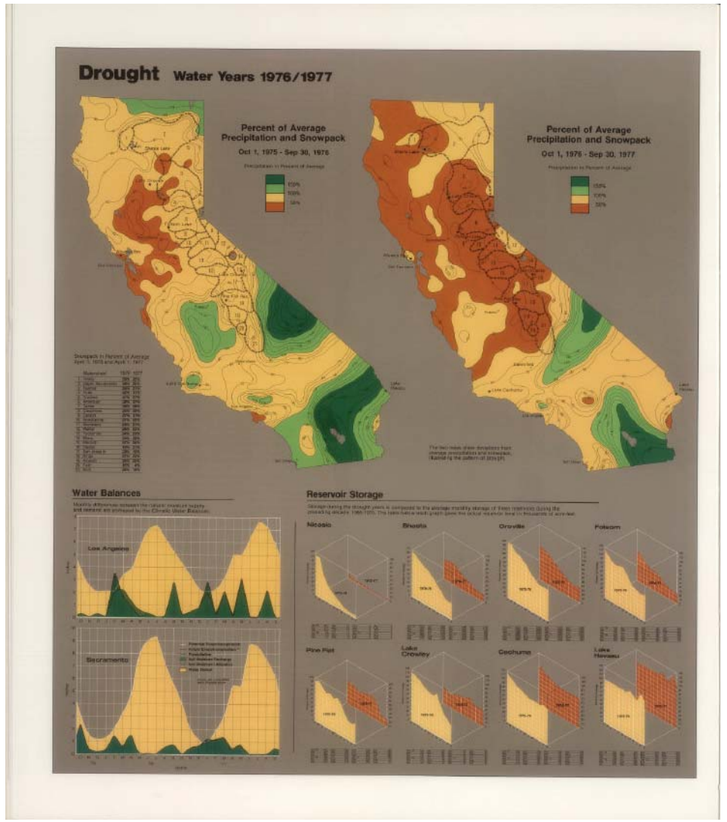
Family Caregiving

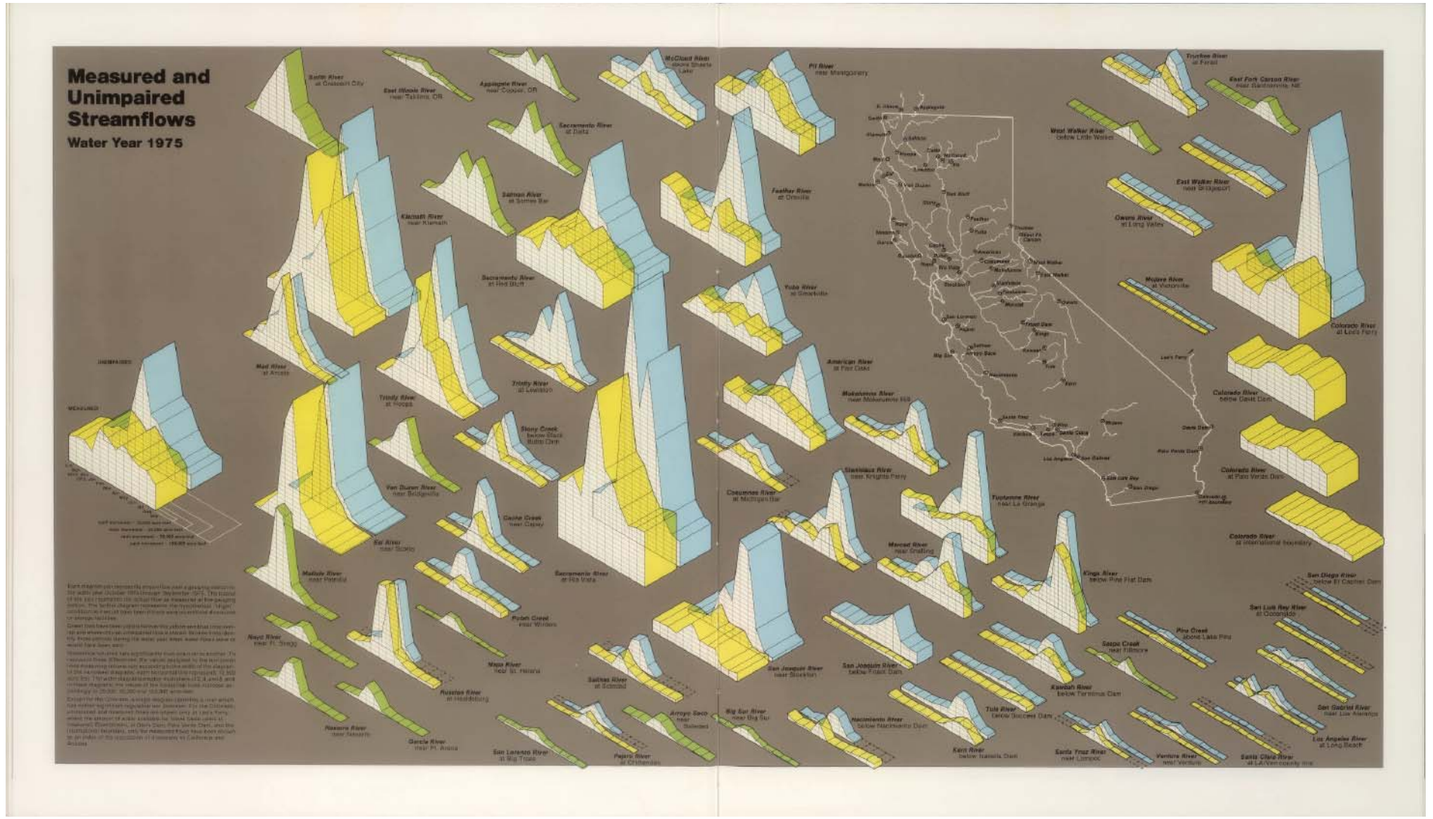
Unfortunately, family caregiving is often overlooked—and rarely studied—in part because it's difficult to measure.



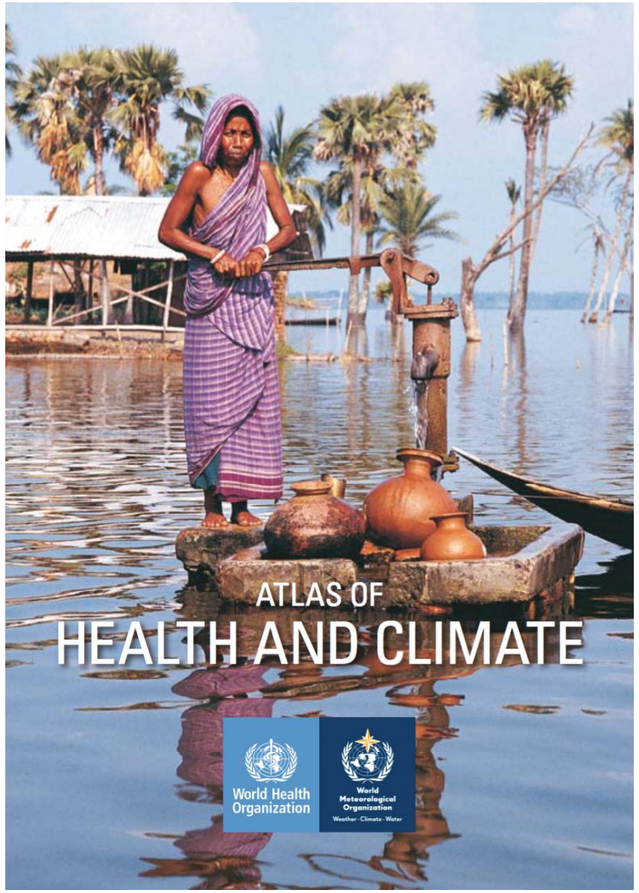
Atlas is a metaphor for comprehensive survey and visualization.

e.g., Stewart Brand's *The California Water Atlas* (1979).

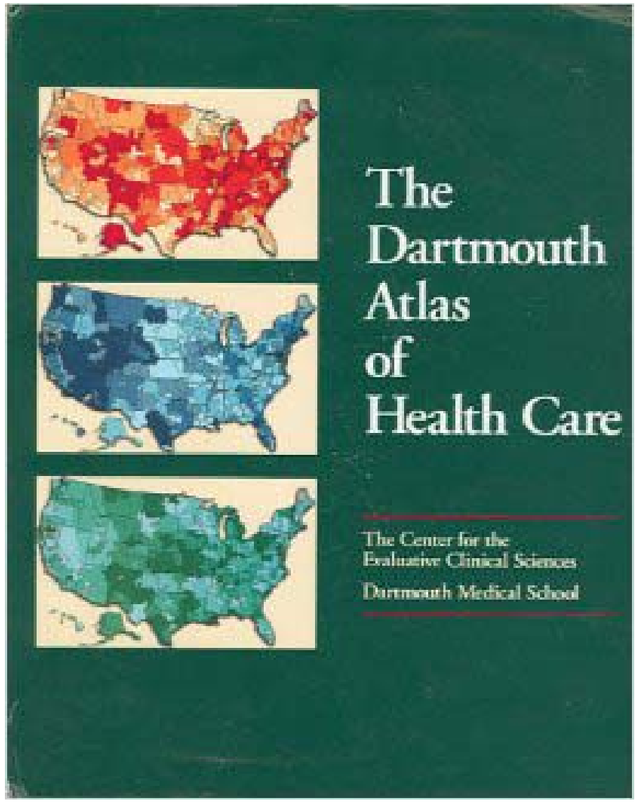




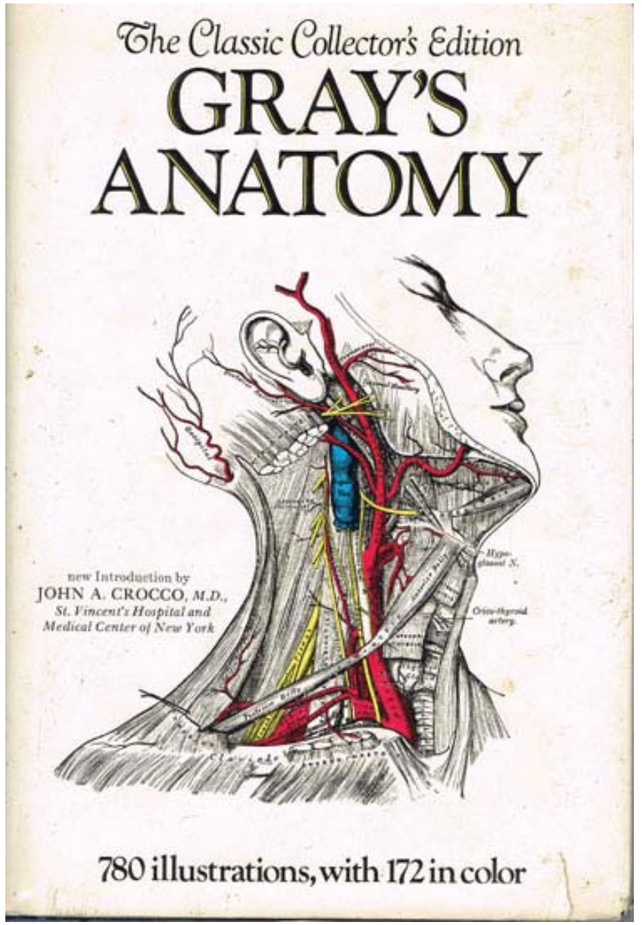
Traditional healthcare has a number of atlases.



Atlas of Health and Climate
World Health Organization

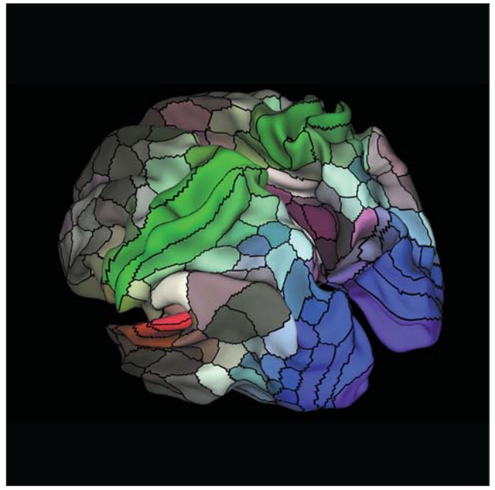


The Dartmouth Atlas of Health Care
Dartmouth Medical School

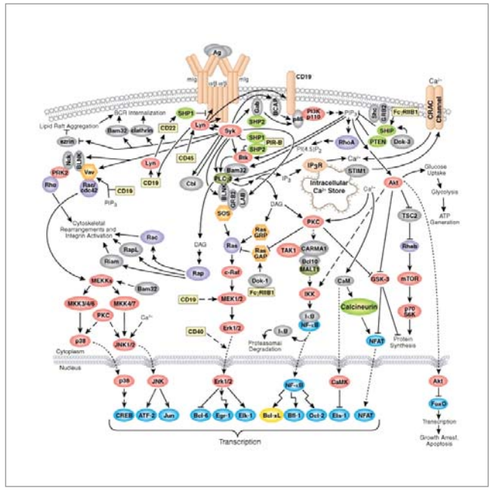


Gray's Anatomy
Henry Gray

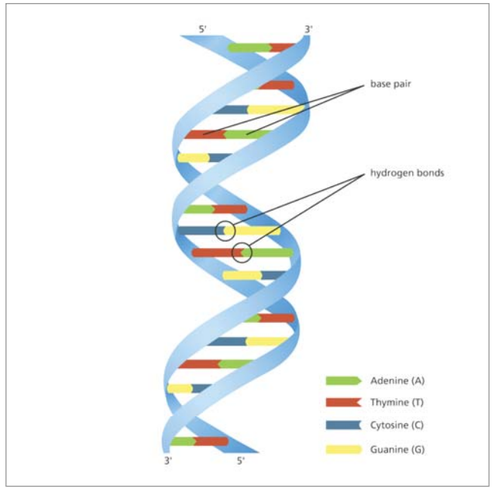
A number of efforts are underway to map body systems.



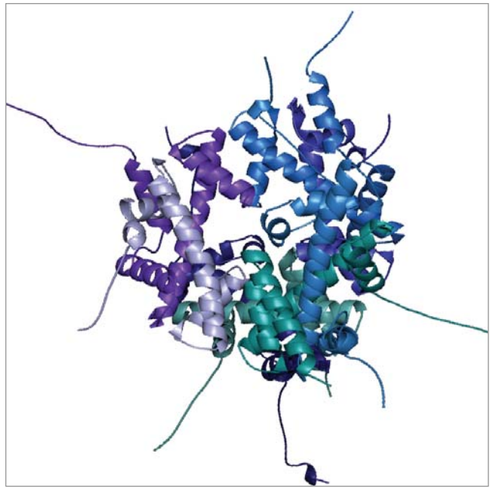
Brain function



Cell signaling pathways



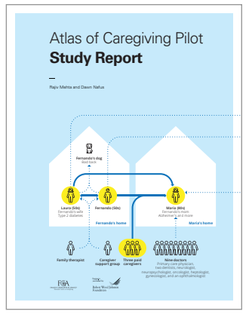
Genomics



Proteomics

We set out to collect measurements and make an atlas of caregiving, or at least a prototype.

Study Report



Data Visualizations

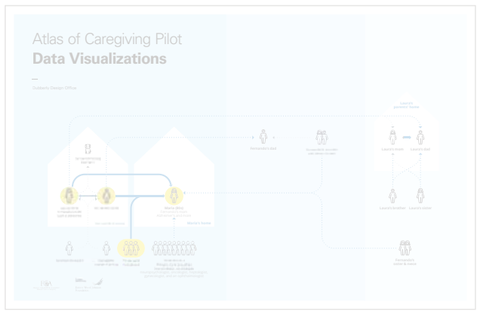
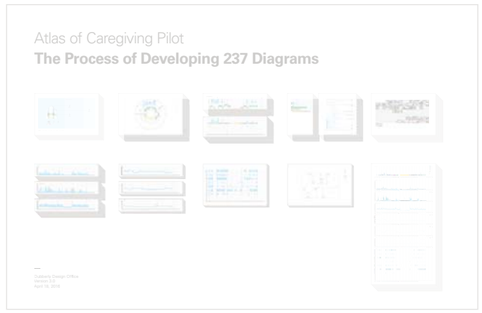


Diagram Development



Care Network Rationale

Website

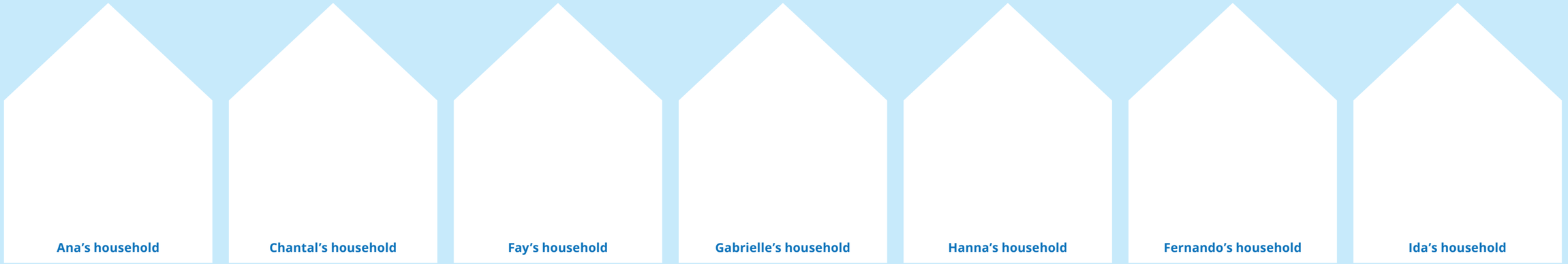
Study Report posted at http://atlasofcaregiving.com/wp-content/uploads/2016/03/Study_Report.pdf

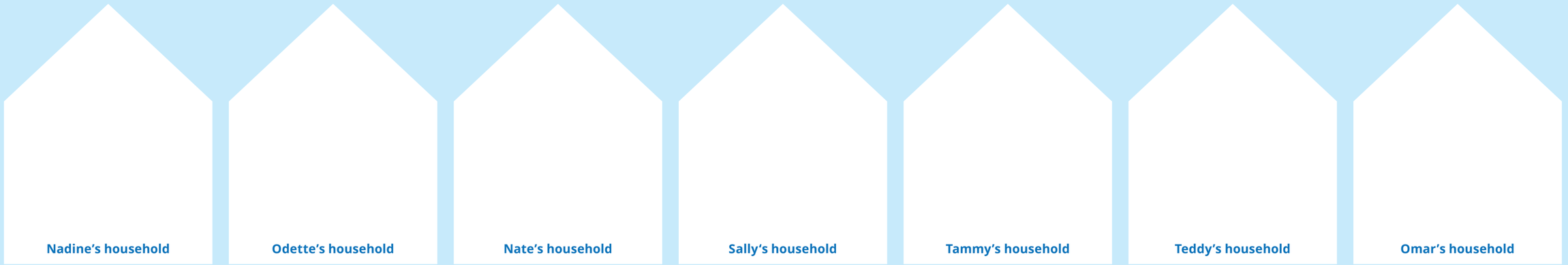
Approach:
How was the study organized?

The key idea was to learn:

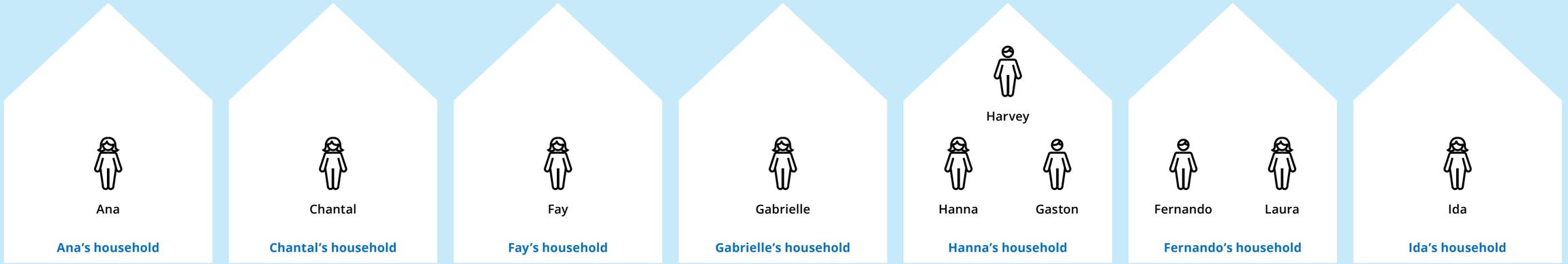
How might IoT sensors augment traditional ethnography in learning about family caregiving?

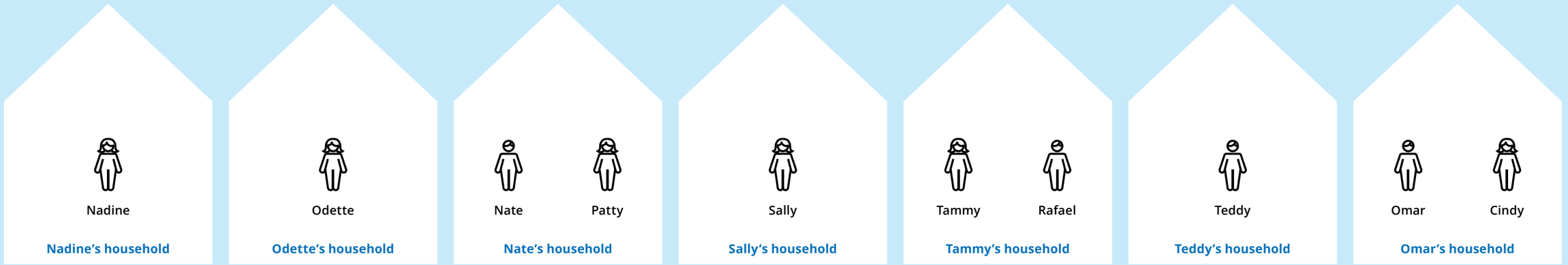
We looked at 14 households



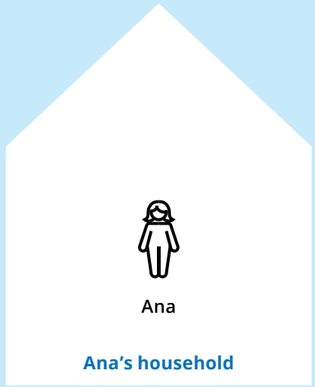


With 20 participants



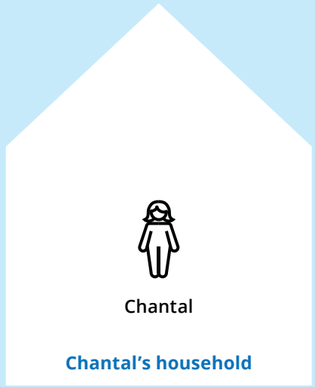


Including over 21 chronic illnesses



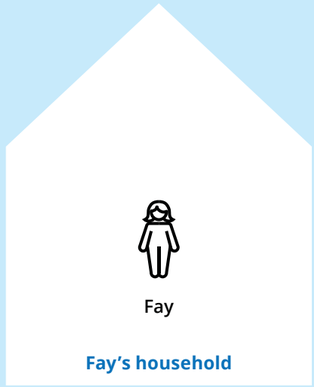
Ana's household

Ana (50s) has had **cystic fibrosis** since birth. She devotes several hours a day to care for her own condition. She also cares for her teenage son Albert, who has **depression**.



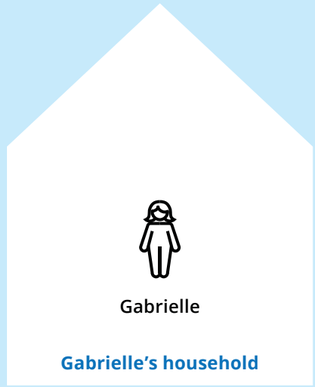
Chantal's household

Chantal (50s) has resigned work to care for her mother Debby (80s) who requires 24x7 care for **dementia**. Additional support comes from a paid home aide and other family members.



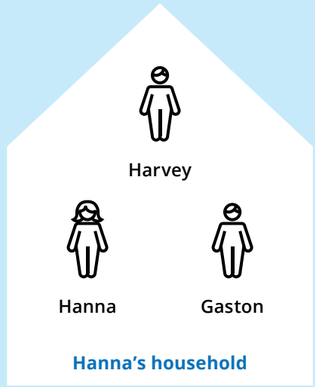
Fay's household

Only-child Fay (30s) cares for her mother Josephine (70s) who has **Alzheimer's**. With no one to help her, she has put PhD studies on hold to provide 24x7 care.



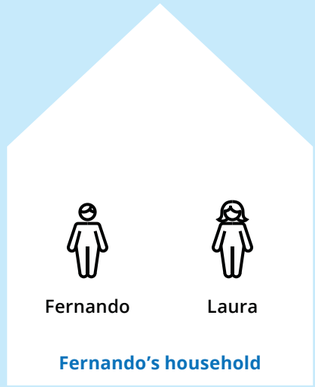
Gabrielle's household

Gabrielle (60s) is the primary caregiver of her mother Karen (101), who has **Alzheimer's**. Gabrielle also has health issues of her own and the sleepless nights and caregiving needs of her mother have taken a toll.



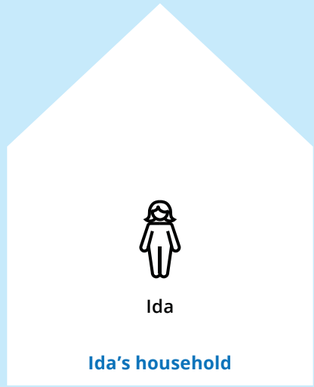
Hanna's household

Hanna and husband Gaston care for her brother Harvey, who has **epilepsy** and **pneumonia/sepsis**. Gaston also cares for his mother, while managing his own **chronic pain** and **edema**. Both Hanna and Gaston also work.



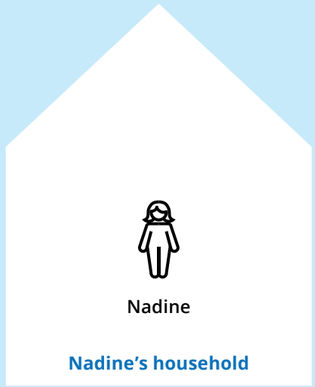
Fernando's household

Fernando and his wife Laura (50s) are the primary caregivers for Fernando's mother Maria (80s) who has **Alzheimer's** disease as well as other health conditions. Together, Fernando and Laura have built a care network to support Maria.



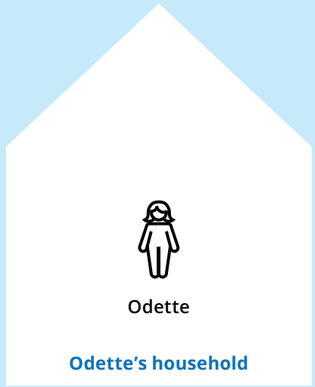
Ida's household

Ida (70s) cares for her husband Ian (70s) who has **Lewy Body Dementia** and **Dysautonomia**. They moved to San Francisco to be nearer to their children two years ago.



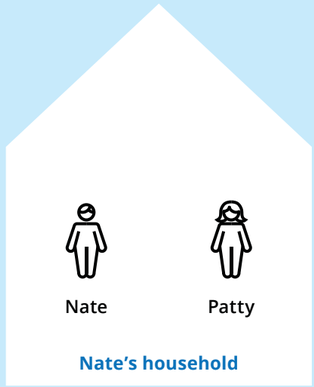
Nadine's household

Nadine (50s) lives with her husband Jerry and two teenage sons, Larry and Karl. Karl has **Type 1 Diabetes**. Nadine is his primary caregiver.



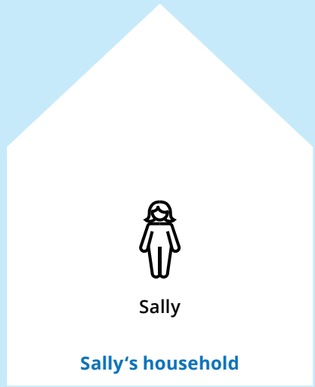
Odette's household

Odette (70s) and her husband Marco (70s) share their home with several other people: their son, son-in-law, and five tenants. Marco has **Parkinson's** disease. Odette is his primary caregiver, but several others are also involved.



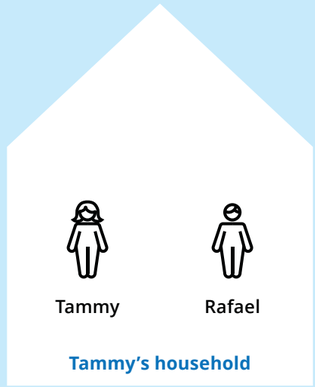
Nate's household

Nate and Patty, both in their 30s, care for each other. Patty has **multiple sclerosis** (MS) and Nate has **glioblastoma**, a terminal condition.



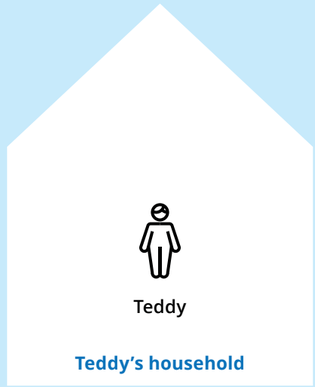
Sally's household

Sally (50s) cares for her son Pablo (20s), who has behavioral and emotional difficulties stemming from **XYY Chromosome Disorder**.



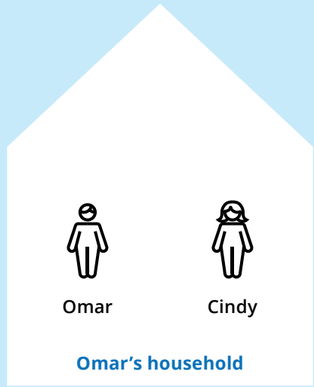
Tammy's household

Tammy (40s) and her husband Rafael (50s) care for their pre-teen children, Wanda and Sam. Wanda has severe **epilepsy** and **cerebral palsy**. She requires 24x7 care. Sam has severe **autism** and also requires a lot of care.



Teddy's household

Teddy (40s) and his wife are the primary caregivers for their two young sons, Van and Walter. Van has **Aspergers (ADHD type)** as well as **encopresis**, and Walter has **cyclical vomiting syndrome**.



Omar's household

Omar (40s) and his separated wife Cindy (40s) share a home with their young son Bob, who has **Aspergers**.

Using 12 sensors

Measuring 16 factors

Photographs
GPS and timestamp

Narrative Clip

Blood Volume Pulse
Calculated to derive heart rate

Acceleration X
Acceleration Y
Acceleration Z
Calculated to derive average motion

Electrodermal Activity
(EDA)

Skin Temperature

Empatica E4

Presence
At home or away

SmartSense Presence Sensor

Motion
In which room and how active

SmartSense Motion Sensors

Humidity
Temperature
Barometric pressure
C02
Noise
Indoor unit

Netatmo Indoor Weather Station

Humidity
Temperature
Outdoor unit

Netatmo Outdoor Weather Station

Over an average of 24 hours

Resulting in 5 GB of data—just from the watch.

The BVP sensor is running at 64 Hz.
That means it makes a reading every
1/64th of a second.
60 seconds comprise a minute;
60 minutes comprise an hour; and
36 hours is the maximum duration of
one of our study sessions.

In other words, one study session
comprises 2,160 minutes,
and just one of the sensors
is collecting 3,840 samples per minute.

That's 8,294,400 samples collected over
the course of one 36-hour session.

8,294,000	samples for BVP (at 64 Hz)
4,147,200	samples for X axis acceleration (at 32 Hz)
4,147,200	samples for Y axis acceleration (at 32 Hz)
4,147,200	samples for Z axis acceleration (at 32 Hz)
518,000	samples for EDA (at 4 Hz)
518,000	samples for skin temperature (at 4 Hz)
21,772,800	samples of raw data for one participant
×19	participants
413,683,200	or nearly half a billion data points

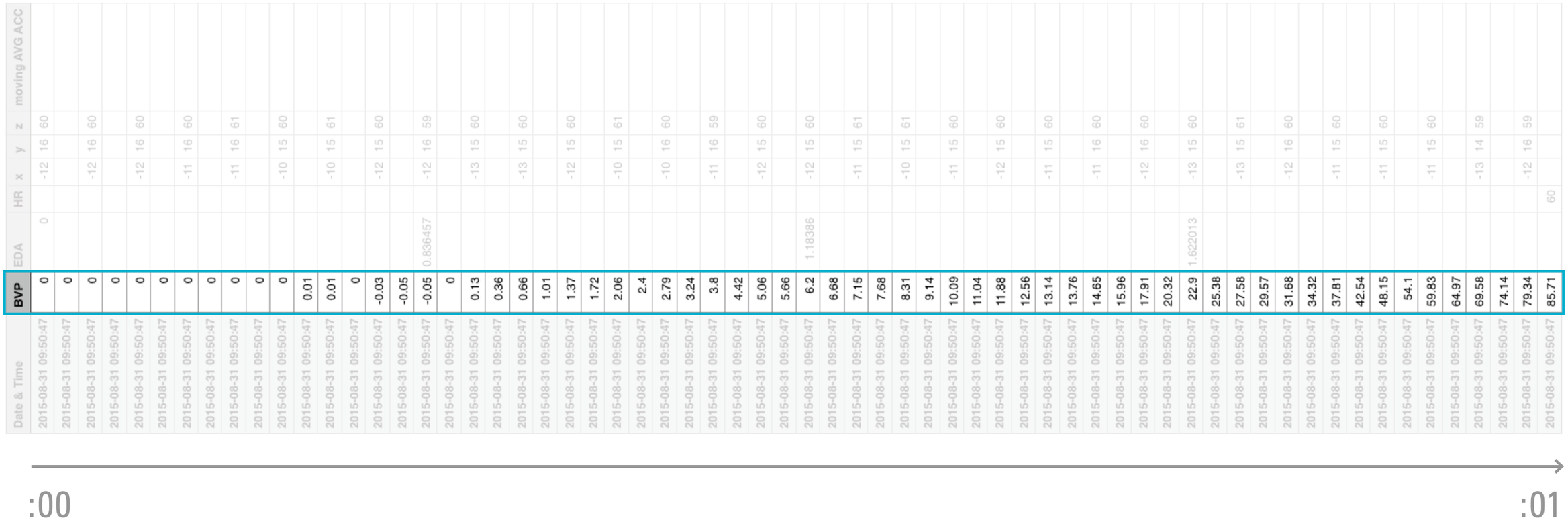
Here’s just 1 second—64 rows—of data from the watch.

Date & Time	BVP	EDA	HR	x	y	z	moving AVG ACC
2015-08-31 09:50:47	0	0		-12	16	60	
2015-08-31 09:50:47	0						
2015-08-31 09:50:47	0			-12	16	60	
2015-08-31 09:50:47	0						
2015-08-31 09:50:47	0			-12	16	60	
2015-08-31 09:50:47	0						
2015-08-31 09:50:47	0			-11	16	60	
2015-08-31 09:50:47	0						
2015-08-31 09:50:47	0			-11	16	61	
2015-08-31 09:50:47	0						
2015-08-31 09:50:47	0			-10	15	60	
2015-08-31 09:50:47	0.01						
2015-08-31 09:50:47	0.01			-10	15	61	
2015-08-31 09:50:47	0						
2015-08-31 09:50:47	-0.03			-12	15	60	
2015-08-31 09:50:47	-0.05						
2015-08-31 09:50:47	-0.05	0.836457		-12	16	59	
2015-08-31 09:50:47	0						
2015-08-31 09:50:47	0.13			-13	15	60	
2015-08-31 09:50:47	0.36						
2015-08-31 09:50:47	0.66			-13	15	60	
2015-08-31 09:50:47	1.01						
2015-08-31 09:50:47	1.37			-12	15	60	
2015-08-31 09:50:47	1.72						
2015-08-31 09:50:47	2.06			-10	15	61	
2015-08-31 09:50:47	2.4						
2015-08-31 09:50:47	2.79			-10	16	60	
2015-08-31 09:50:47	3.24						
2015-08-31 09:50:47	3.8			-11	16	59	
2015-08-31 09:50:47	4.42						
2015-08-31 09:50:47	5.06			-12	15	60	
2015-08-31 09:50:47	5.66						
2015-08-31 09:50:47	6.2	1.18386		-12	15	60	
2015-08-31 09:50:47	6.68						
2015-08-31 09:50:47	7.15			-11	15	61	
2015-08-31 09:50:47	7.68						
2015-08-31 09:50:47	8.31			-10	15	61	
2015-08-31 09:50:47	9.14						
2015-08-31 09:50:47	10.09			-11	15	60	
2015-08-31 09:50:47	11.04						
2015-08-31 09:50:47	11.88			-12	15	60	
2015-08-31 09:50:47	12.56						
2015-08-31 09:50:47	13.14			-11	15	60	
2015-08-31 09:50:47	13.76						
2015-08-31 09:50:47	14.65			-11	16	60	
2015-08-31 09:50:47	15.96						
2015-08-31 09:50:47	17.91			-12	16	60	
2015-08-31 09:50:47	20.32						
2015-08-31 09:50:47	22.9	1.622013		-13	15	60	
2015-08-31 09:50:47	25.38						
2015-08-31 09:50:47	27.58			-13	15	61	
2015-08-31 09:50:47	29.57						
2015-08-31 09:50:47	31.68			-12	16	60	
2015-08-31 09:50:47	34.32						
2015-08-31 09:50:47	37.81			-11	15	60	
2015-08-31 09:50:47	42.54						
2015-08-31 09:50:47	48.15			-11	15	60	
2015-08-31 09:50:47	54.1						
2015-08-31 09:50:47	59.83			-11	15	60	
2015-08-31 09:50:47	64.97						
2015-08-31 09:50:47	69.58			-13	14	59	
2015-08-31 09:50:47	74.14						
2015-08-31 09:50:47	79.34			-12	16	59	
2015-08-31 09:50:47	85.71		60				

:00 → :01

Here's just 1 second—64 rows—of data from the watch.

BVP is measured at 64 Hz so there's data in every row.

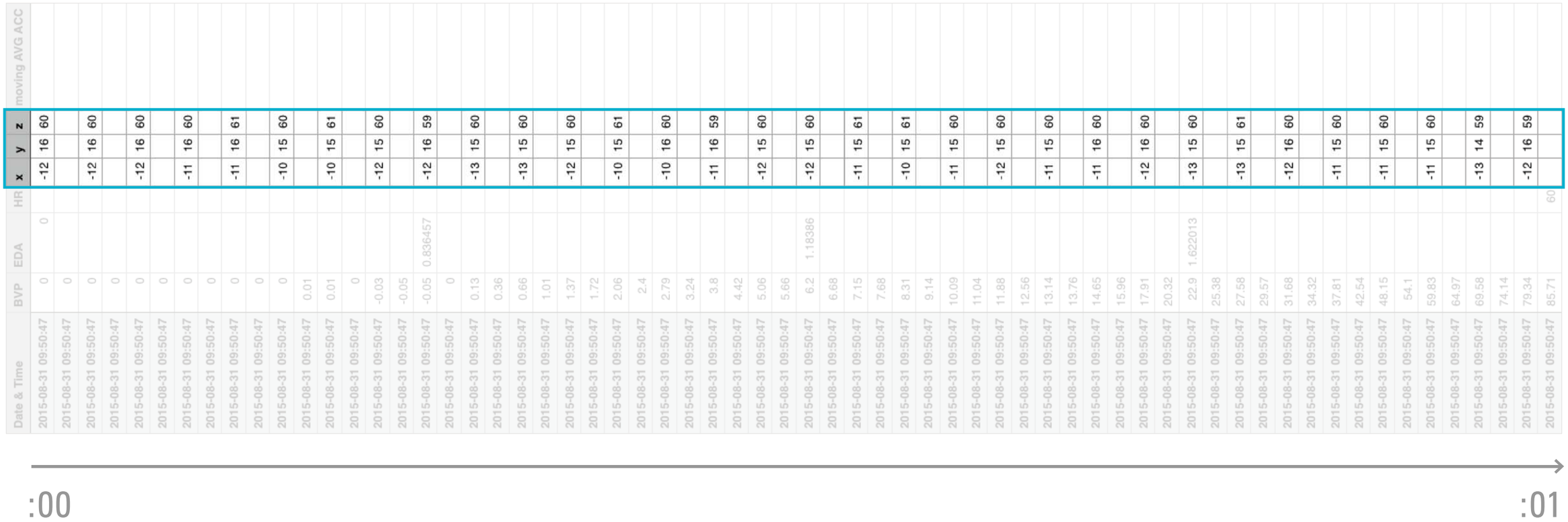


Date & Time	BVP	EDA	HR	x	y	z	moving AVG ACC
2015-08-31 09:50:47	0	0		-12	16	60	
2015-08-31 09:50:47	0						
2015-08-31 09:50:47	0			-12	16	60	
2015-08-31 09:50:47	0						
2015-08-31 09:50:47	0			-12	16	60	
2015-08-31 09:50:47	0						
2015-08-31 09:50:47	0			-11	16	60	
2015-08-31 09:50:47	0						
2015-08-31 09:50:47	0			-11	16	61	
2015-08-31 09:50:47	0						
2015-08-31 09:50:47	0			-10	15	60	
2015-08-31 09:50:47	0						
2015-08-31 09:50:47	0.01			-10	15	61	
2015-08-31 09:50:47	0.01						
2015-08-31 09:50:47	0			-12	15	60	
2015-08-31 09:50:47	-0.03			-12	15	60	
2015-08-31 09:50:47	-0.05						
2015-08-31 09:50:47	-0.05	0.836457		-12	16	59	
2015-08-31 09:50:47	0						
2015-08-31 09:50:47	0.13			-13	15	60	
2015-08-31 09:50:47	0.36						
2015-08-31 09:50:47	0.66			-13	15	60	
2015-08-31 09:50:47	1.01						
2015-08-31 09:50:47	1.37			-12	15	60	
2015-08-31 09:50:47	1.72						
2015-08-31 09:50:47	2.06			-10	15	61	
2015-08-31 09:50:47	2.4						
2015-08-31 09:50:47	2.79			-10	16	60	
2015-08-31 09:50:47	3.24						
2015-08-31 09:50:47	3.8			-11	16	59	
2015-08-31 09:50:47	4.42						
2015-08-31 09:50:47	5.06			-12	15	60	
2015-08-31 09:50:47	5.66						
2015-08-31 09:50:47	6.2	1.18386		-12	15	60	
2015-08-31 09:50:47	6.68						
2015-08-31 09:50:47	7.15			-11	15	61	
2015-08-31 09:50:47	7.68						
2015-08-31 09:50:47	8.31			-10	15	61	
2015-08-31 09:50:47	9.14						
2015-08-31 09:50:47	10.09			-11	15	60	
2015-08-31 09:50:47	11.04						
2015-08-31 09:50:47	11.88			-12	15	60	
2015-08-31 09:50:47	12.56						
2015-08-31 09:50:47	13.14			-11	15	60	
2015-08-31 09:50:47	13.76						
2015-08-31 09:50:47	14.65			-11	16	60	
2015-08-31 09:50:47	15.96						
2015-08-31 09:50:47	17.91			-12	16	60	
2015-08-31 09:50:47	20.32						
2015-08-31 09:50:47	22.9	1.622013		-13	15	60	
2015-08-31 09:50:47	25.38						
2015-08-31 09:50:47	27.58			-13	15	61	
2015-08-31 09:50:47	29.57						
2015-08-31 09:50:47	31.68			-12	16	60	
2015-08-31 09:50:47	34.32						
2015-08-31 09:50:47	37.81			-11	15	60	
2015-08-31 09:50:47	42.54						
2015-08-31 09:50:47	48.15			-11	15	60	
2015-08-31 09:50:47	54.1						
2015-08-31 09:50:47	59.83			-11	15	60	
2015-08-31 09:50:47	64.97						
2015-08-31 09:50:47	69.58			-13	14	59	
2015-08-31 09:50:47	74.14						
2015-08-31 09:50:47	79.34			-12	16	59	
2015-08-31 09:50:47	85.71		60				

:00 :01

Here's just 1 second—64 rows—of data from the watch.

XYZ acceleration is measured at 32 Hz so there's data in every other row.



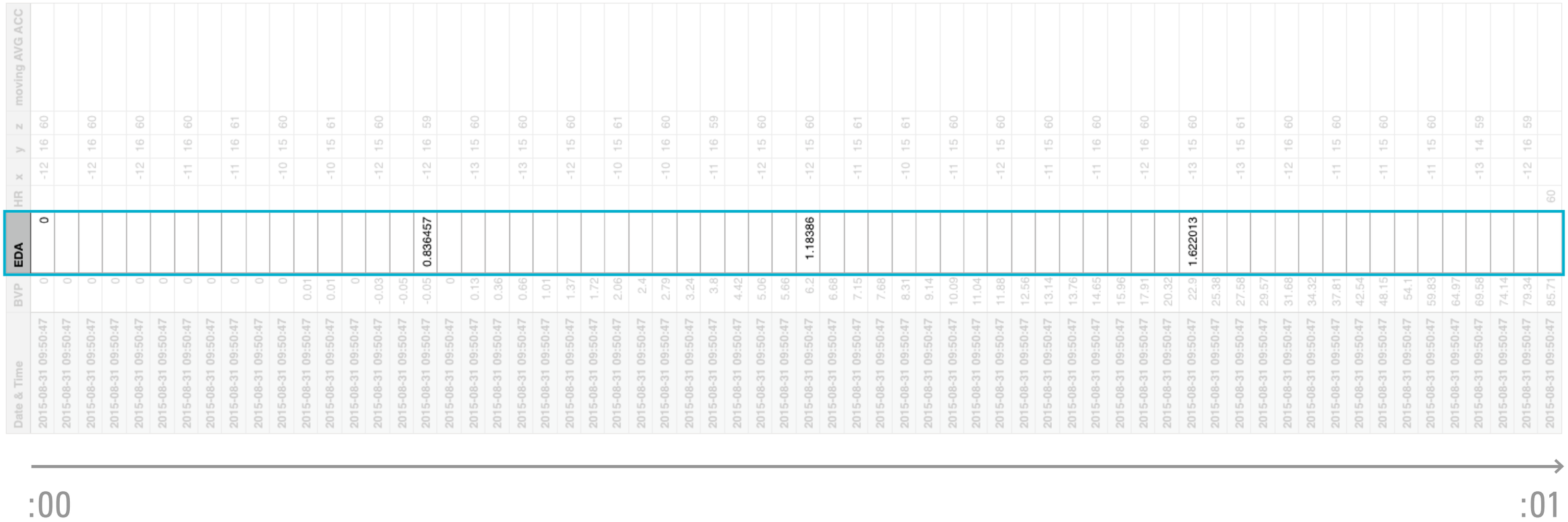
Date & Time	BVP	EDA	HR	x	y	z	moving AVG ACC
2015-08-31 09:50:47	0	0	0	-12	16	60	
2015-08-31 09:50:47	0	0					
2015-08-31 09:50:47	0	0		-12	16	60	
2015-08-31 09:50:47	0	0					
2015-08-31 09:50:47	0	0		-12	16	60	
2015-08-31 09:50:47	0	0					
2015-08-31 09:50:47	0	0		-11	16	60	
2015-08-31 09:50:47	0	0					
2015-08-31 09:50:47	0	0		-11	16	61	
2015-08-31 09:50:47	0	0					
2015-08-31 09:50:47	0	0		-10	15	60	
2015-08-31 09:50:47	0.01	0					
2015-08-31 09:50:47	0.01	0		-10	15	61	
2015-08-31 09:50:47	0	0					
2015-08-31 09:50:47	-0.03	0		-12	15	60	
2015-08-31 09:50:47	-0.05	0					
2015-08-31 09:50:47	-0.05	0.836457		-12	16	59	
2015-08-31 09:50:47	0	0					
2015-08-31 09:50:47	0.13	0		-13	15	60	
2015-08-31 09:50:47	0.36	0					
2015-08-31 09:50:47	0.66	0		-13	15	60	
2015-08-31 09:50:47	1.01	0					
2015-08-31 09:50:47	1.37	0		-12	15	60	
2015-08-31 09:50:47	1.72	0					
2015-08-31 09:50:47	2.06	0		-10	15	61	
2015-08-31 09:50:47	2.4	0					
2015-08-31 09:50:47	2.79	0		-10	16	60	
2015-08-31 09:50:47	3.24	0					
2015-08-31 09:50:47	3.8	0		-11	16	59	
2015-08-31 09:50:47	4.42	0					
2015-08-31 09:50:47	5.06	0		-12	15	60	
2015-08-31 09:50:47	5.66	0					
2015-08-31 09:50:47	6.2	1.18386		-12	15	60	
2015-08-31 09:50:47	6.68	0					
2015-08-31 09:50:47	7.15	0		-11	15	61	
2015-08-31 09:50:47	7.68	0					
2015-08-31 09:50:47	8.31	0		-10	15	61	
2015-08-31 09:50:47	9.14	0					
2015-08-31 09:50:47	10.09	0		-11	15	60	
2015-08-31 09:50:47	11.04	0					
2015-08-31 09:50:47	11.88	0		-12	15	60	
2015-08-31 09:50:47	12.56	0					
2015-08-31 09:50:47	13.14	0		-11	15	60	
2015-08-31 09:50:47	13.76	0					
2015-08-31 09:50:47	14.65	0		-11	16	60	
2015-08-31 09:50:47	15.96	0					
2015-08-31 09:50:47	17.91	0		-12	16	60	
2015-08-31 09:50:47	20.32	0					
2015-08-31 09:50:47	22.9	1.622013		-13	15	60	
2015-08-31 09:50:47	25.38	0					
2015-08-31 09:50:47	27.58	0		-13	15	61	
2015-08-31 09:50:47	29.57	0					
2015-08-31 09:50:47	31.68	0		-12	16	60	
2015-08-31 09:50:47	34.32	0					
2015-08-31 09:50:47	37.81	0		-11	15	60	
2015-08-31 09:50:47	42.54	0					
2015-08-31 09:50:47	48.15	0		-11	15	60	
2015-08-31 09:50:47	54.1	0					
2015-08-31 09:50:47	59.83	0		-11	15	60	
2015-08-31 09:50:47	64.97	0					
2015-08-31 09:50:47	69.58	0		-13	14	59	
2015-08-31 09:50:47	74.14	0					
2015-08-31 09:50:47	79.34	0		-12	16	59	
2015-08-31 09:50:47	85.71	0	60				

:00

:01

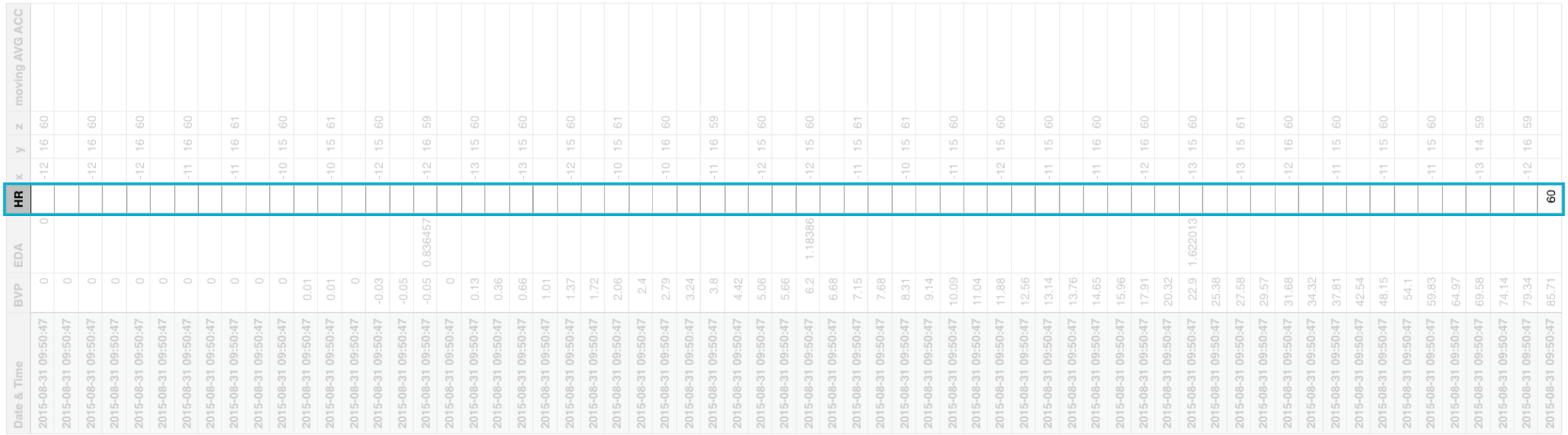
Here's just 1 second—64 rows—of data from the watch.

EDA is measured at 4 Hz so there's data in every 15 rows.



Here's just 1 second—64 rows—of data from the watch.

Heart Rate is measured at 1 Hz so there's data in every 64 rows.



Even more data was collected from the environment and motion sensors.

589	average samples from environment
4,176	average samples from motion
4,765	average samples of raw data for one participant
×8	participants (not all households opted-in for instrumentation)
38,120	data points for environment and motion

Measurements: What data was collected?

We compiled all the data visualizations into their own document so they could be shown at full size.

Study Report

Data Visualizations

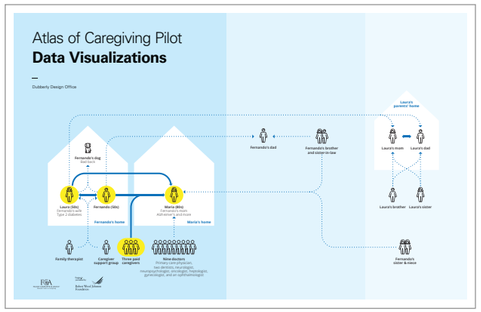
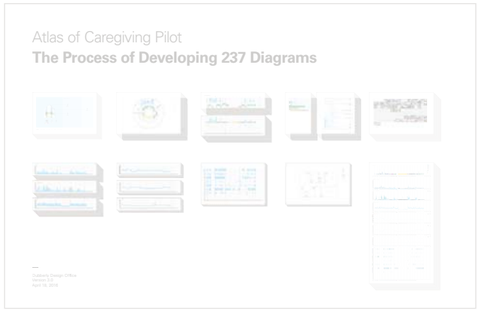


Diagram Development



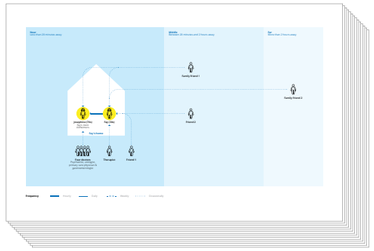
Care Network Rationale

Website

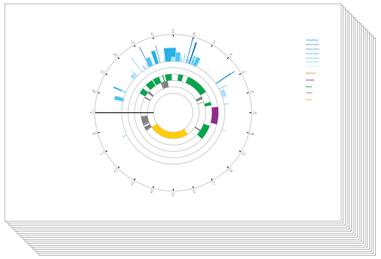
Data Visualizations posted at http://atlasofcaregiving.com/wp-content/uploads/2016/03/Data_Visualizations.pdf

The “Data Visualizations” document contains 237 unique diagrams

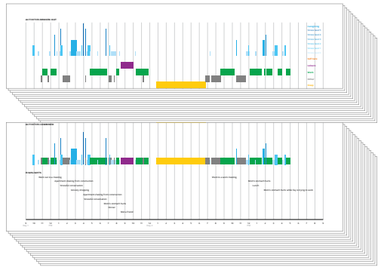
Care Network × 14 participants



24-hour Log × 18 participants



36-hour Log 2 plots × 18 participants = 36



Activities 2 plots × 18 participants = 36

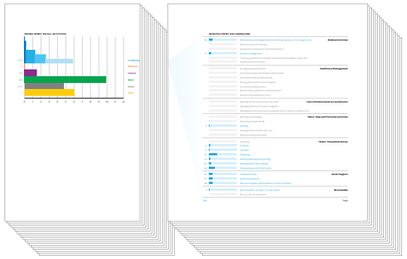
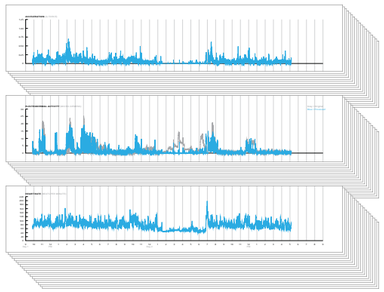
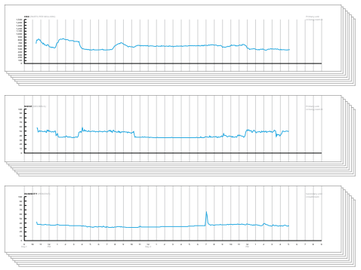


Photo Log × 20 participants

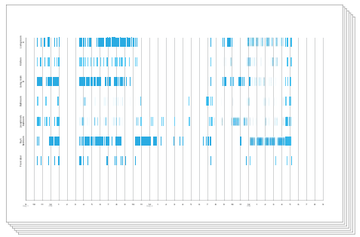
Body 3 plots × 19 participants = 57



Environment 3 plots × 8 participants = 24

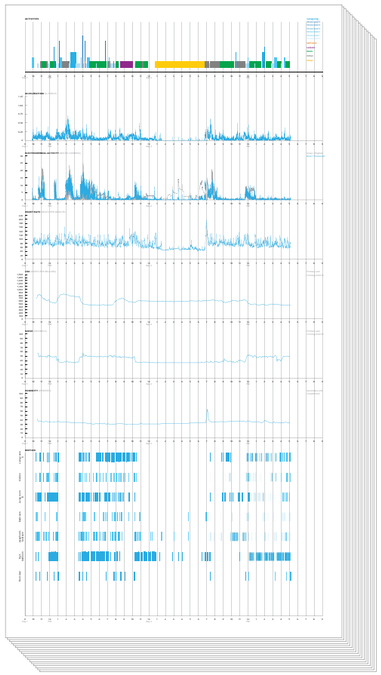


Motion × 7 participants

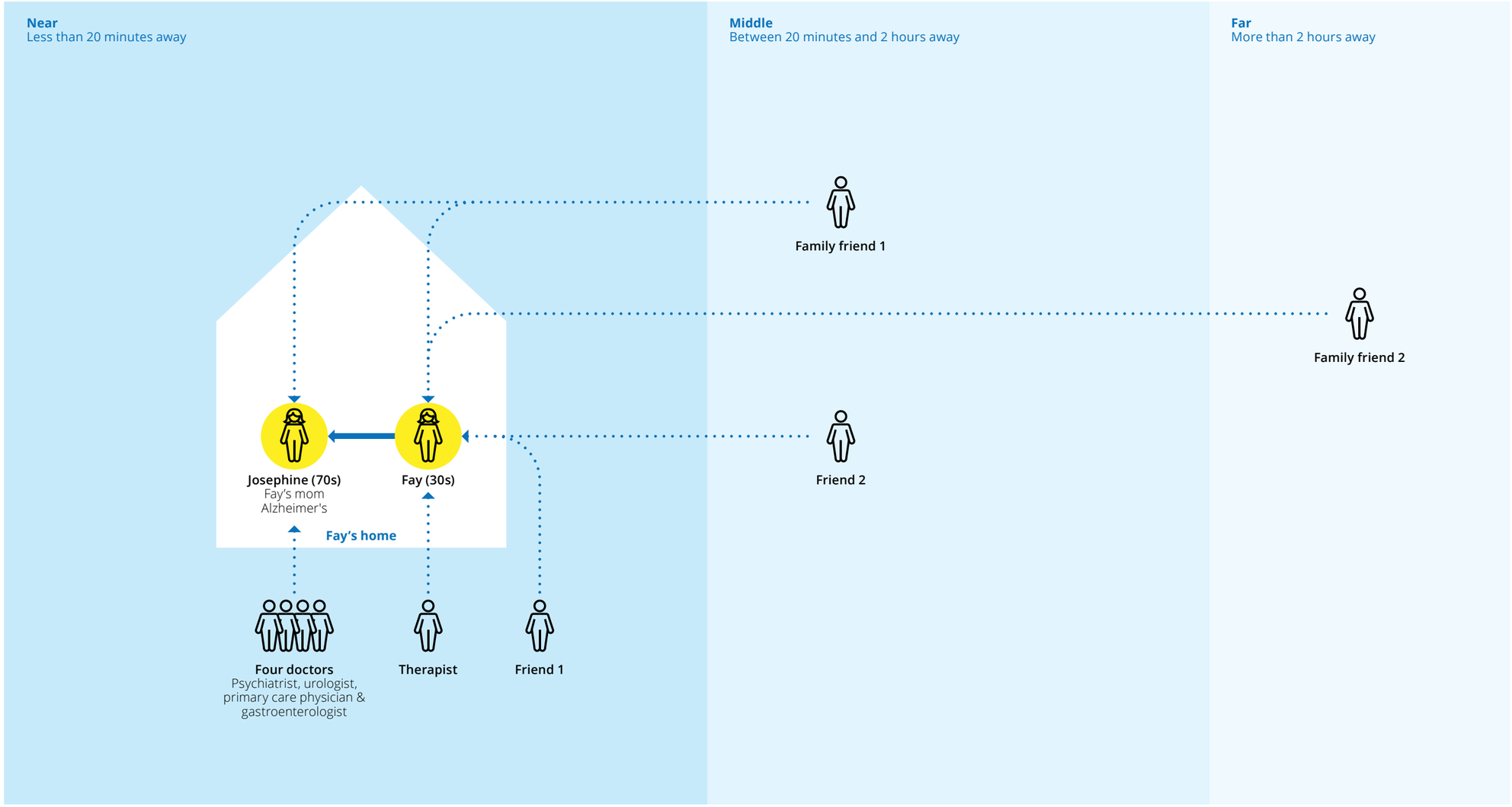


Floorplan × 7 participants

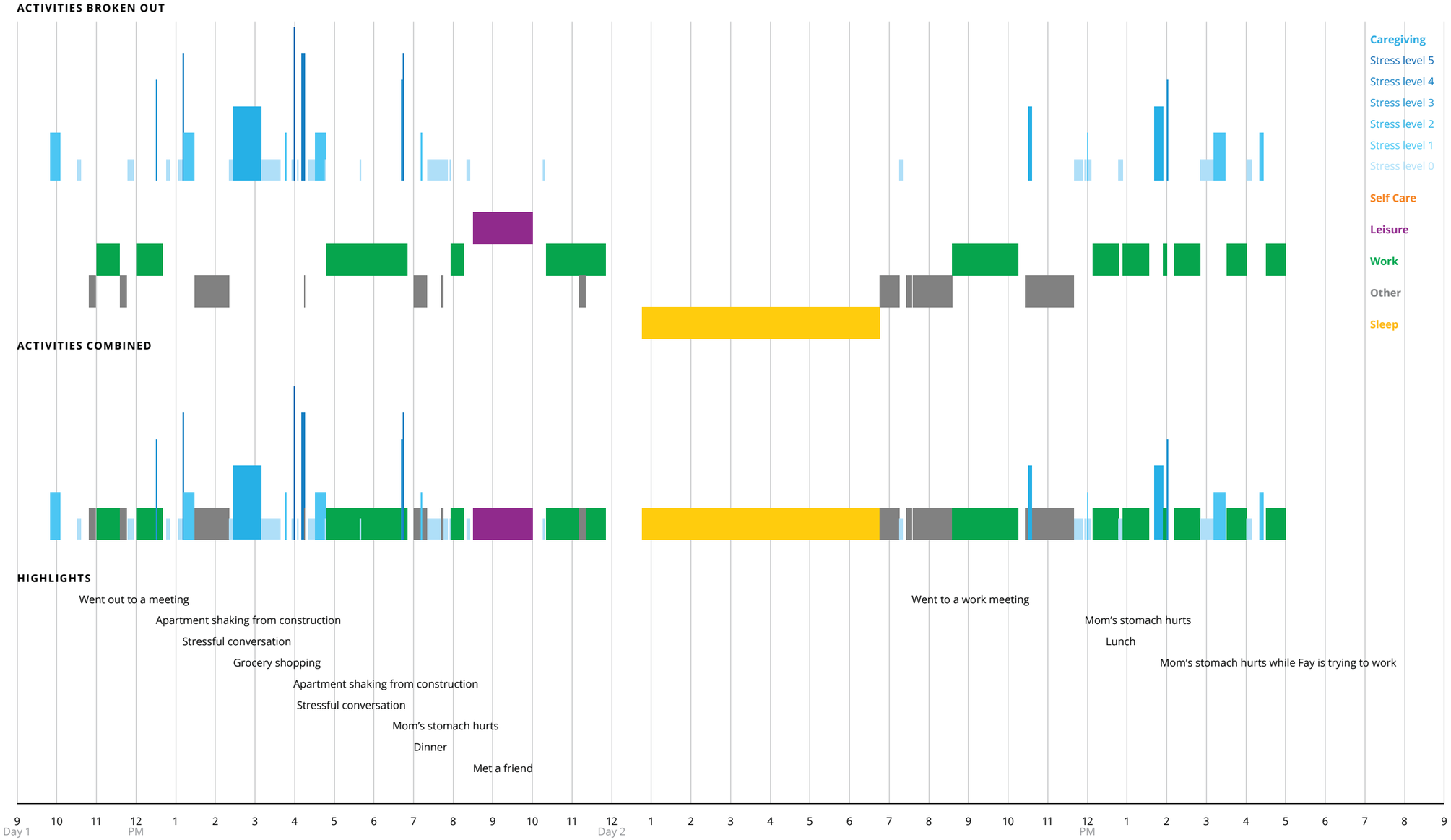
Summary × 18 participants



Care network for Fay ×14 additional participants

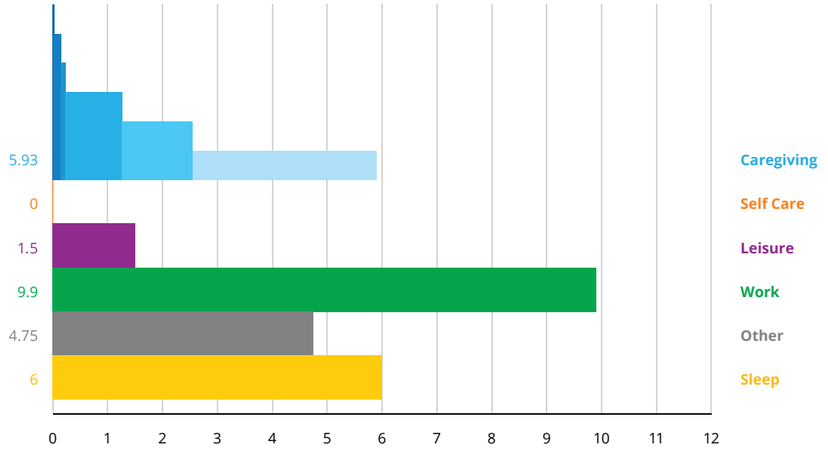


36-hour log for Fay ×18 additional participants



Activity log for Fay ×18 additional participants

HOURS SPENT ON ALL ACTIVITIES



MINUTES SPENT ON CAREGIVING

36	Medications and supplements (including injections, IVs, oxygen, etc.)	**Medical Activities**
	Exercise, physical therapy	
	Equipment preparation and maintenance	
17	Wound management	
	Tracking symptoms and body measurements (weight, temp, etc.)	
	Preparing special meals	
	Arranging appointments	**Healthcare Management**
	Communicating with health professionals	
	Visits with health professionals	
	Buying prescriptions and supplies	
	Insurance and payments	
	Researching conditions and treatments	
	Researching healthcare costs	
	Keeping family and friends informed	**Care Communication & Coordination**
	Managing family and paid caregivers	
	Managing community services (paratransit, meals on wheels, etc.)	
	Bathing and toileting	**“ADLs” Help with Personal Activities**
	Dressing and grooming	
6	Feeding	
	Getting in/out of bed, chair, etc	
	Moving around the home	
	Cleaning	**“IADLs” Household Chores**
9	Cooking	
5	Laundry	
77	Shopping	
12	Getting/Moving/Using things	
22	Managing bills and savings	
60	Transportation to/from home	
32	Companionship	**Social Support**
37	Emotional support	
38	Plan and support participation in social activities	
5	Be constantly “on alert” for any needs	**Be Available**
	Be “on-call” for problems	
356		Total

Photo log for Fay ×20 additional participants

Black squares replace recognizable faces to ensure privacy.

Gray squares indicate when participants turned the camera off.

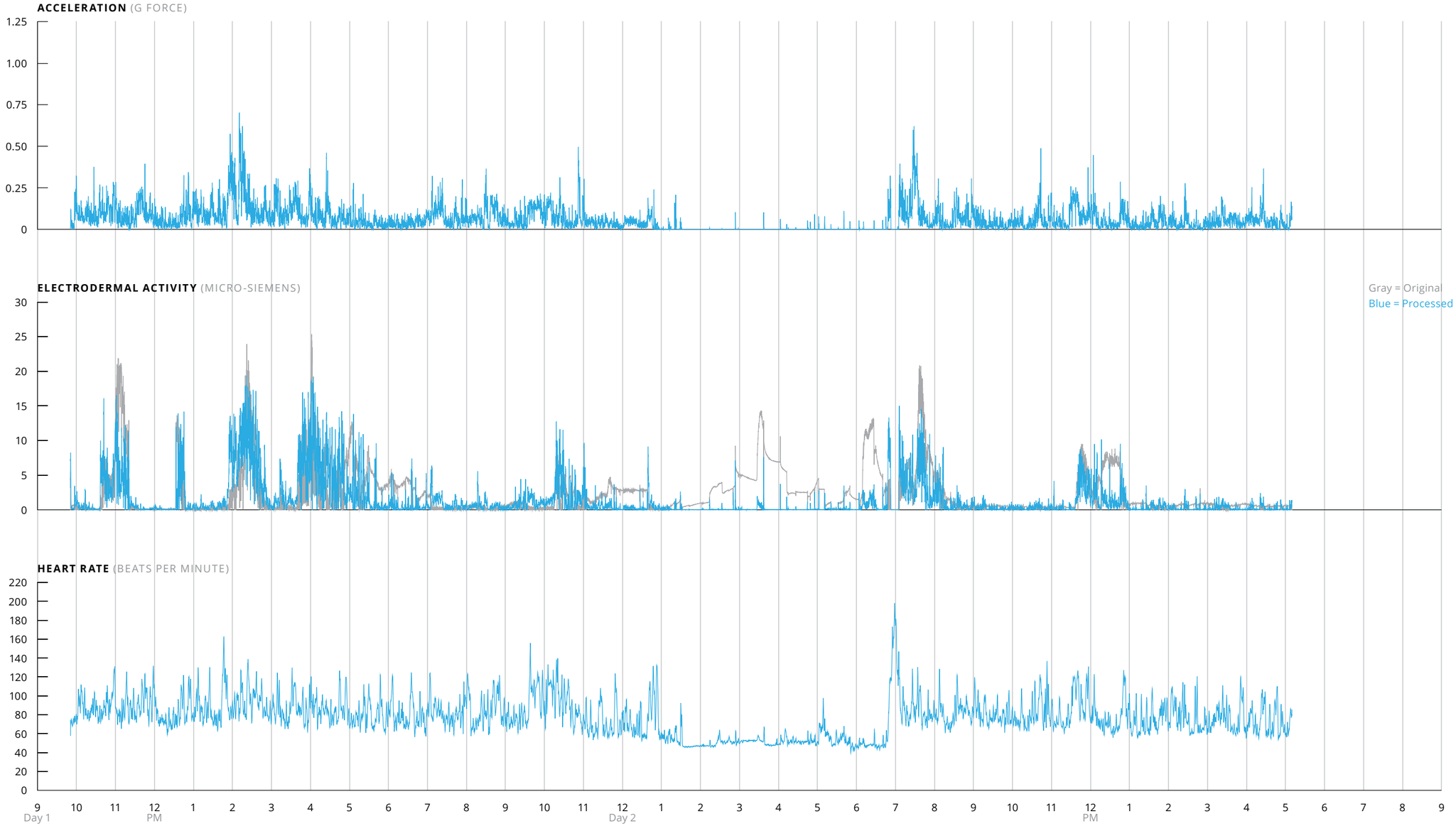
White squares indicate the start and stop of the study.

There were 974 photos for Fay alone.

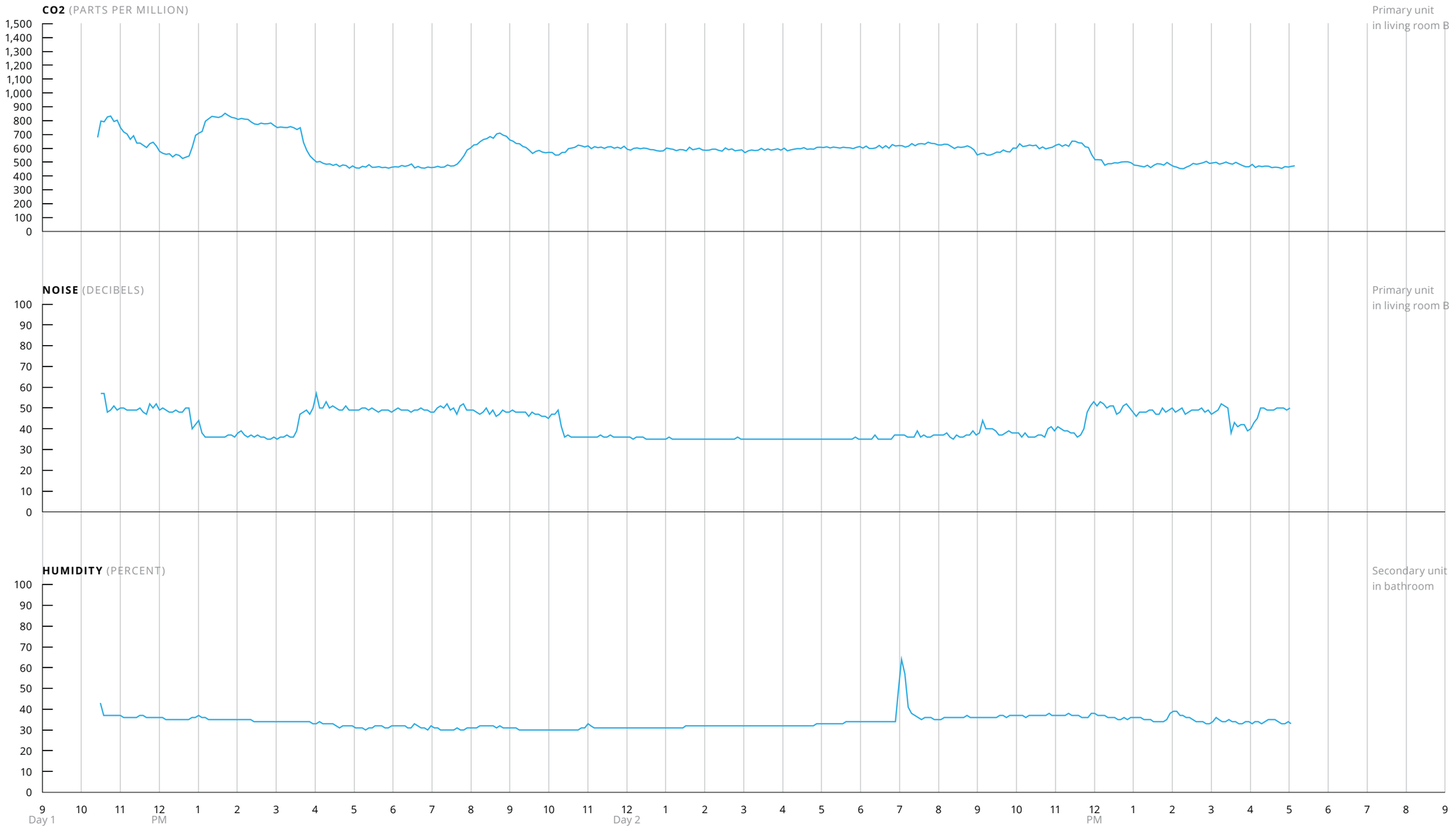
Counts depend on study length;
one participant had over 1,500 photos.

2015-08-31T195724.jpg
2015-08-31T195824.jpg
2015-08-31T195957.jpg
2015-08-31T201731.jpg
2015-08-31T201801.jpg
2015-08-31T201834.jpg
2015-08-31T201904.jpg
2015-08-31T201934.jpg
2015-08-31T202006.jpg
2015-08-31T202036.jpg
2015-08-31T202106.jpg
2015-08-31T202138.jpg
2015-08-31T202208.jpg
2015-08-31T202310.jpg
2015-08-31T202340.jpg
2015-08-31T202747.jpg
2015-08-31T202843.jpg
2015-08-31T221547.jpg
2015-08-31T221617.jpg
2015-08-31T221747.jpg
2015-08-31T223000.jpg
2015-08-31T223030.jpg
2015-08-31T223100.jpg
2015-08-31T223131.jpg
2015-08-31T223201.jpg
2015-08-31T223231.jpg
2015-08-31T223303.jpg
2015-08-31T223333.jpg
2015-08-31T223403.jpg
2015-08-31T223434.jpg
2015-08-31T223504.jpg
2015-08-31T223534.jpg
2015-08-31T223608.jpg
2015-08-31T223638.jpg
2015-08-31T223708.jpg
2015-08-31T223740.jpg
2015-08-31T223811.jpg
2015-08-31T223841.jpg
2015-08-31T223912.jpg
2015-08-31T223942.jpg

Body sensor diagrams for Fay ×19 additional participants

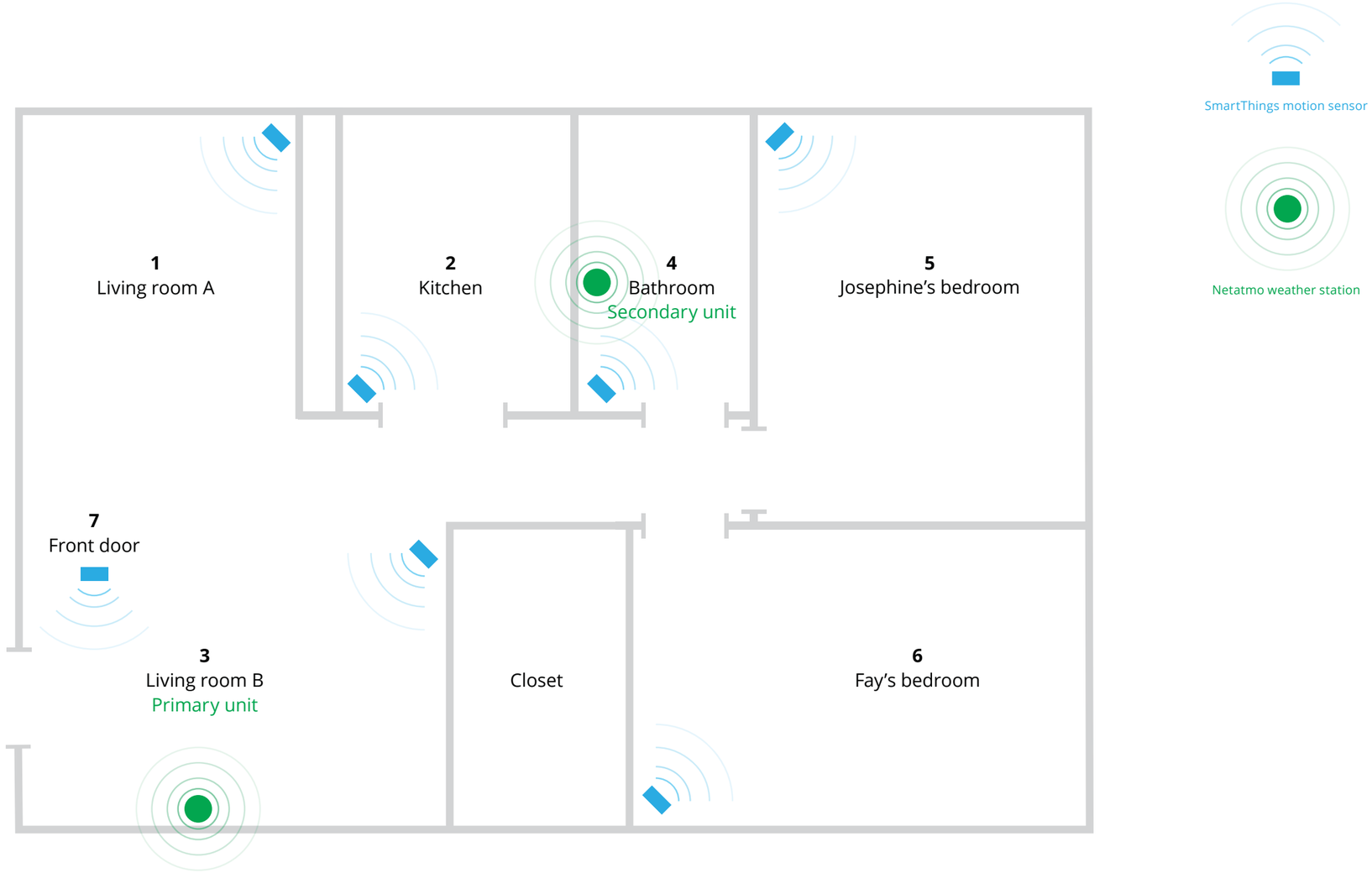


Environmental sensor diagrams for Fay ×8 additional participants

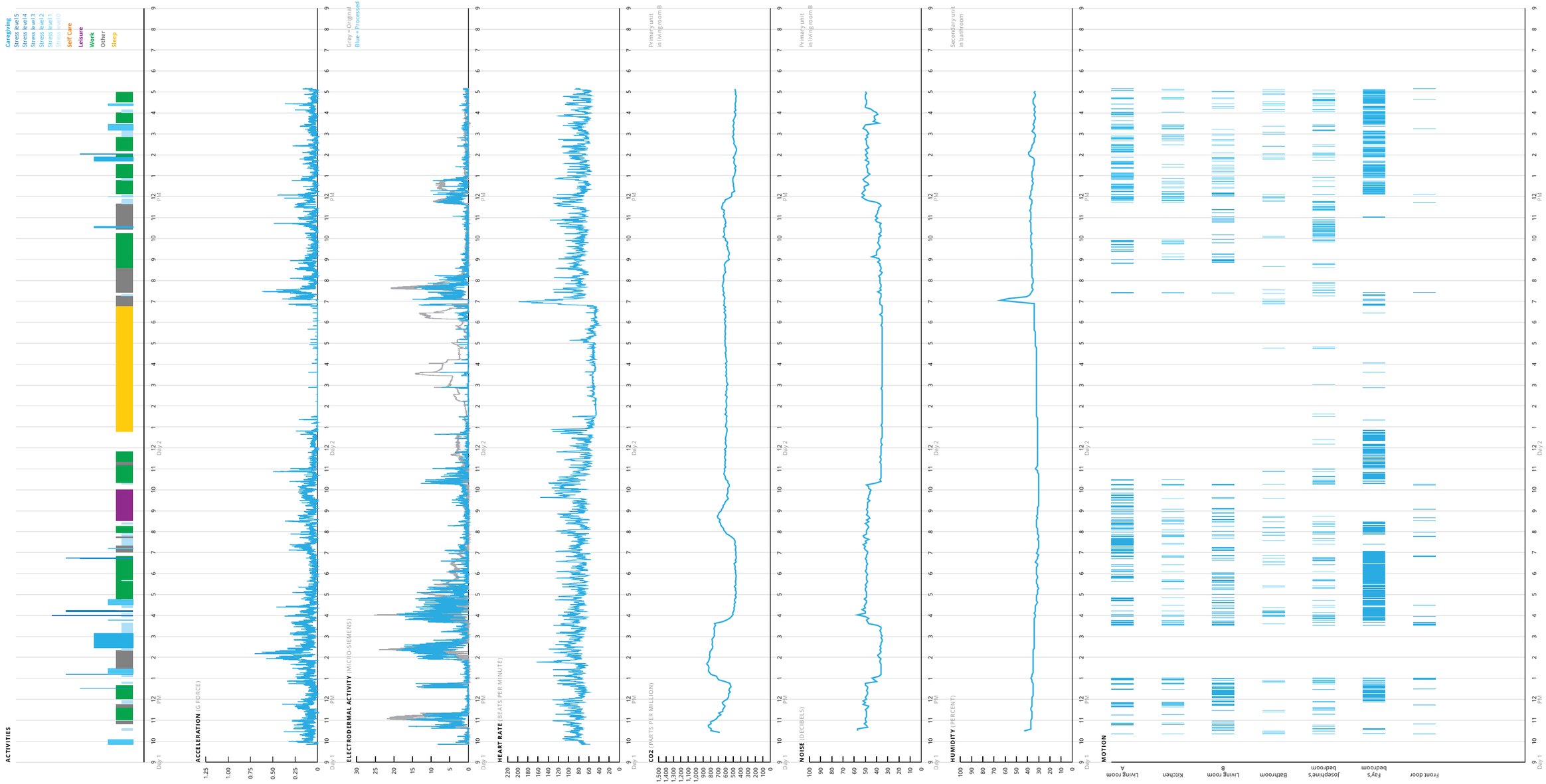


Motion sensors diagram for Fay ×7 additional participants

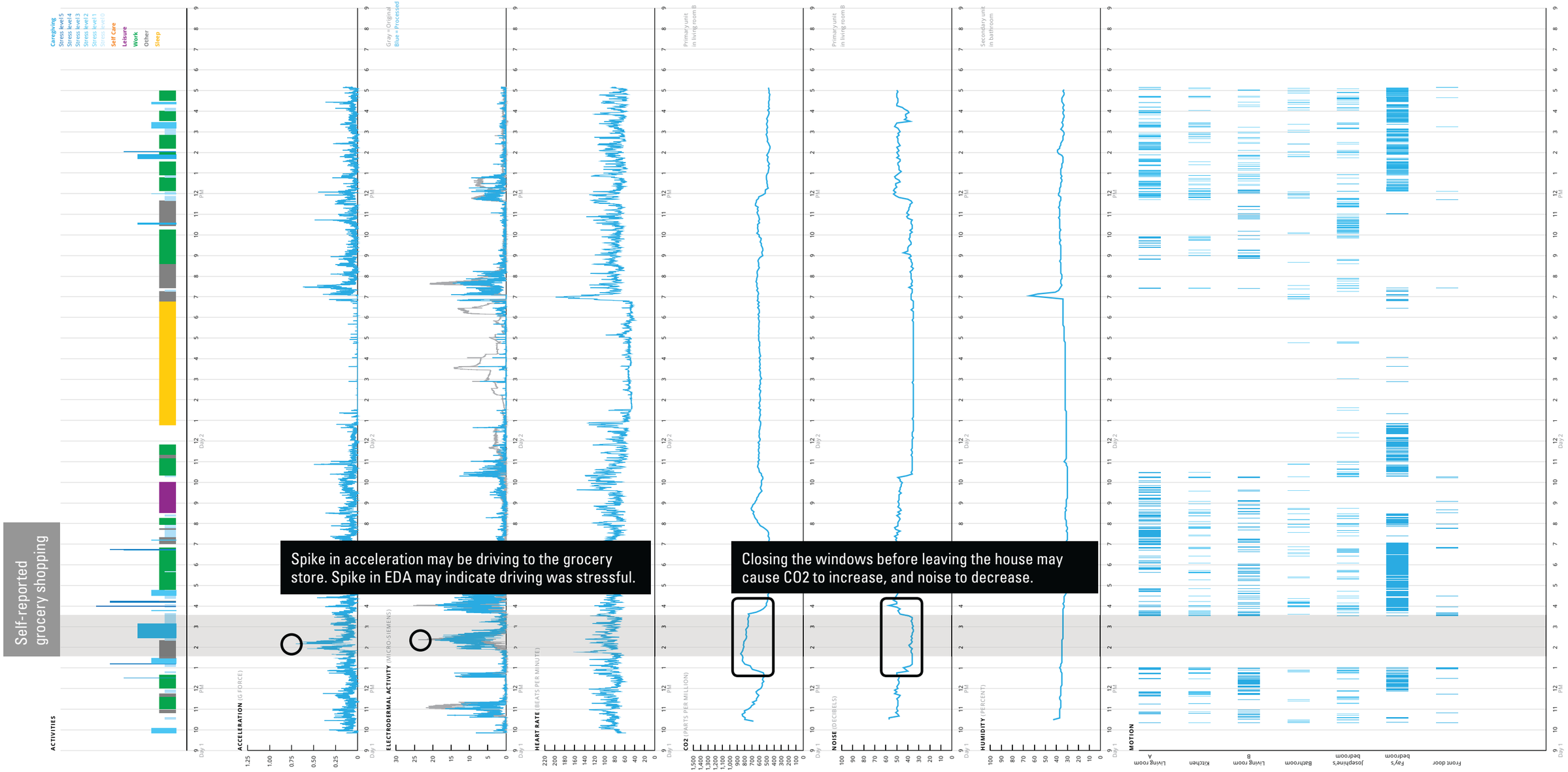
Floorplan with sensor locations for Fay ×7 additional participants



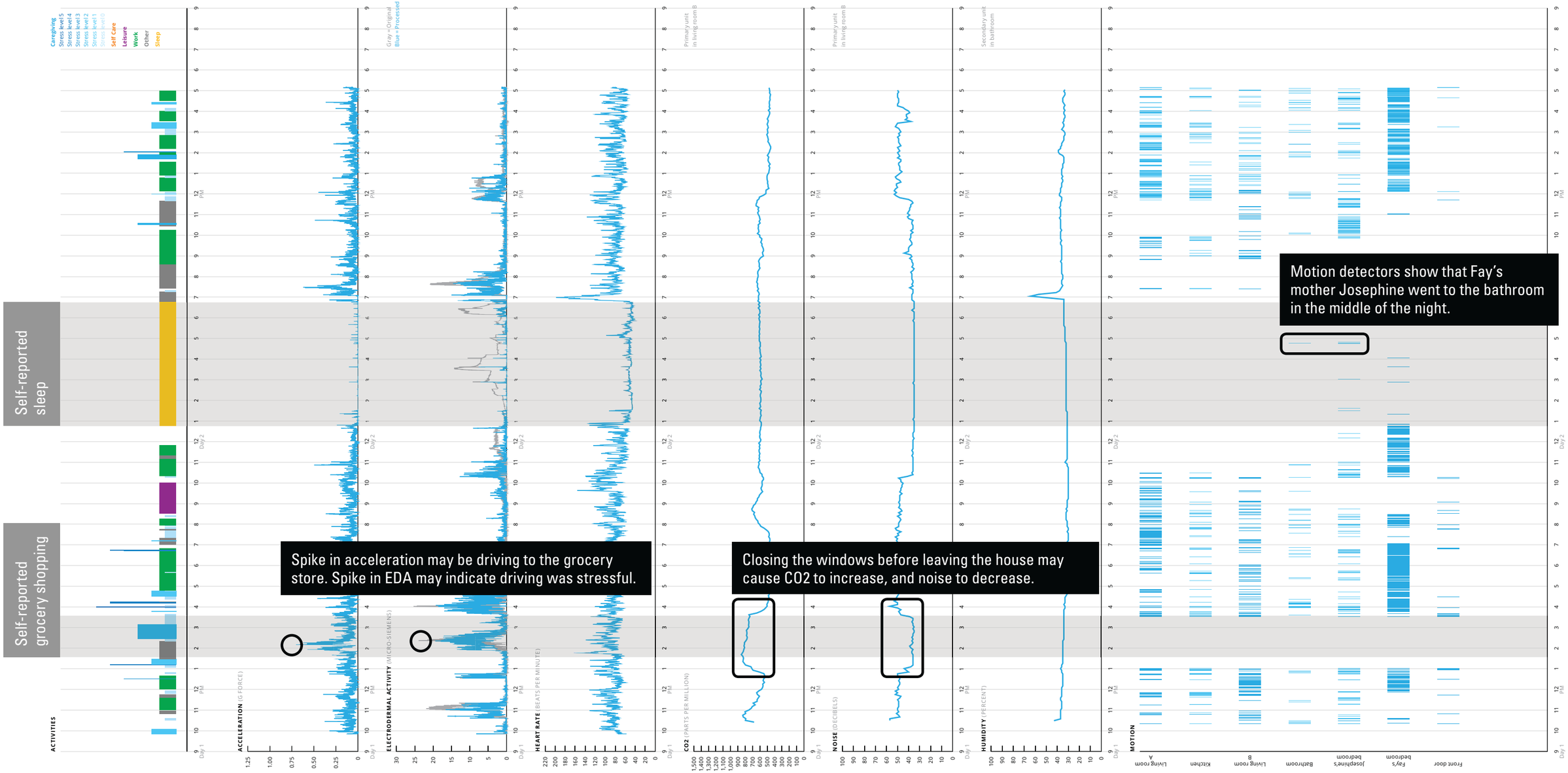
Summary diagram for Fay ×18 additional participants



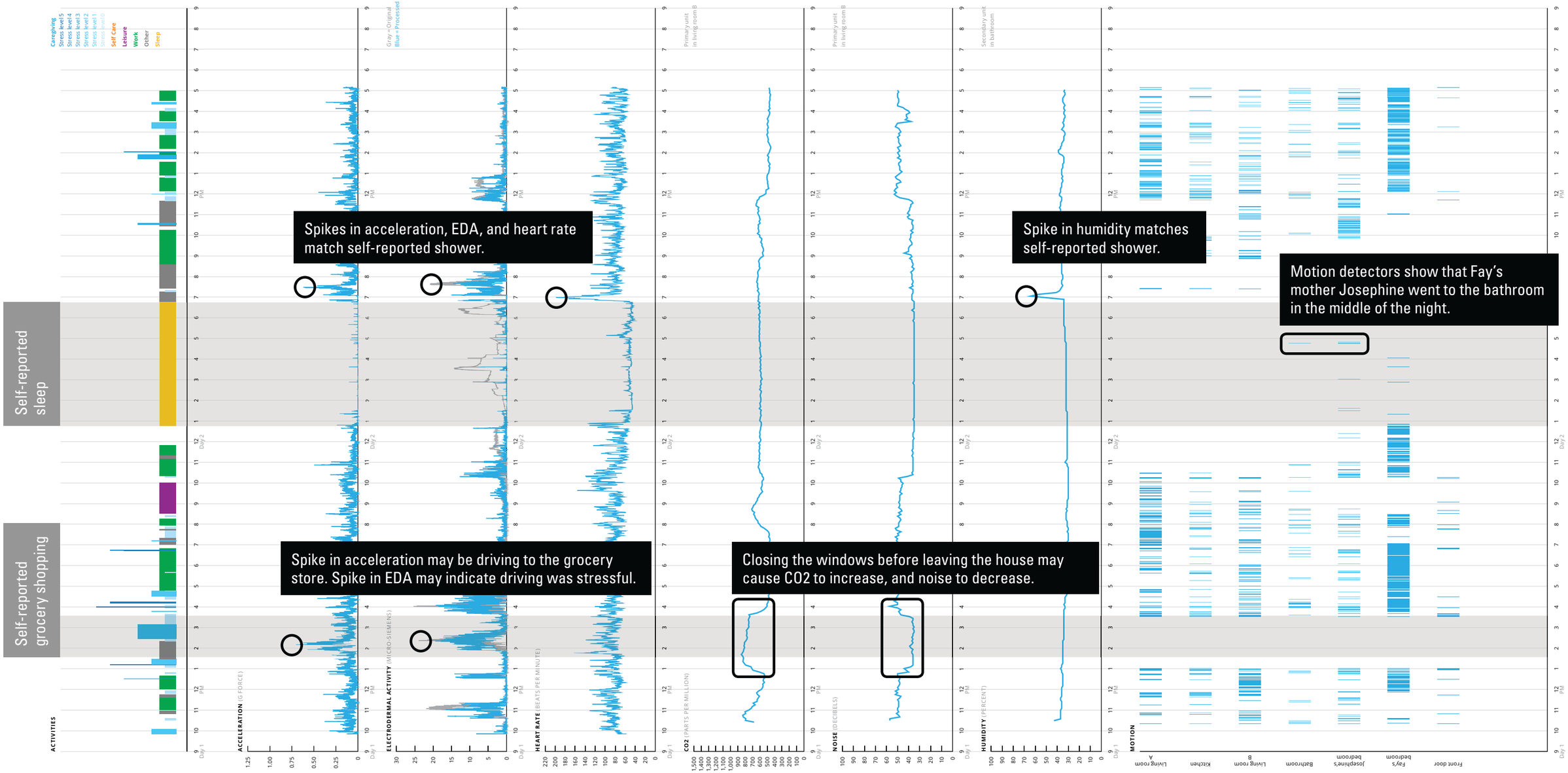
Analyzing Fay's summary diagram for insights—afternoon



Analyzing Fay's summary diagram for insights—**night**



Analyzing Fay's summary diagram for insights—**morning**



PART FOUR

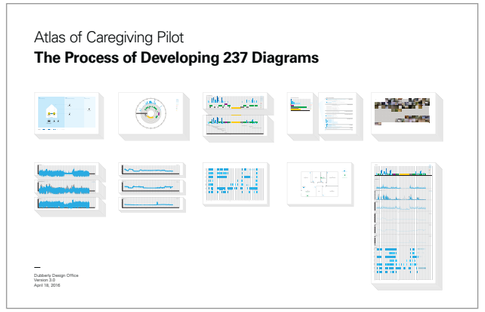
Visualizations: How was the data processed?

We created the ‘Diagram Development’ document to capture all the details that went into the making of the data visualizations.

Study Report

Data Visualizations

Diagram Development



Care Network Rationale

Website

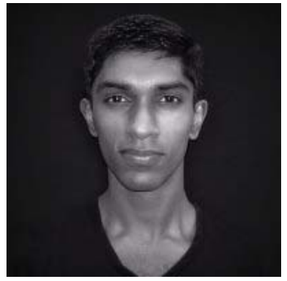
Diagram Development posted at http://staging.dubberly.com/atlas/160504-Final_Documents/AoC_Development_160505a.pdf

This project included help from 15 people.

John Cain
Sapient
Sensor and data expert

Peter Binggeser
Sapient
Sensor and data expert

Aniket Bhatnagar
Sapient
Sensor and data expert

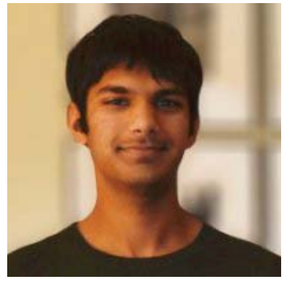


Pasindu Wewegama
Sapient
Sensor and data expert

Elliott Hedman
mPath
Sensor expert

Dawn Nafus
Intel
Ethnography

Rajiv Mehta
Bhageera
Principal Investigator



Shalin Mehta
Coding and production

Patch Kessler
Tyto Life
Data wrangling, filtering, and MatLab graphing

Hugh Dubberly
Dubberly Design Office
Co-Principal Investigator

Robin Bahr
Dubberly Design Office
Project management

Ryan Reposar
Dubberly Design Office
Design, data wrangling, and production

Paul Souza
Dubberly Design Office
Exploration, data wrangling, and design.

Knut Synstad
Dubberly Design Office
Design and production

Cody Wackerman
Dubberly Design Office
Design, coding, and production

The team used a wide range of tools.

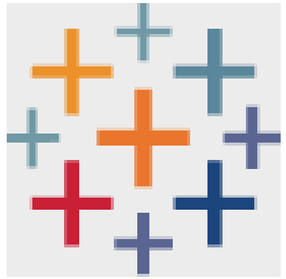

Narrative


Empatica

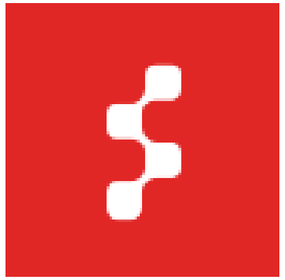

SmartThings

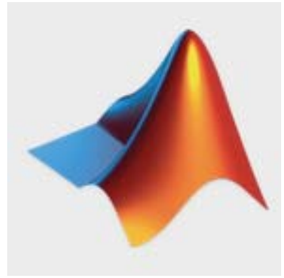
Netatmo

Data Viz Tool



Tableau


Sapient Datadeer


MatLab


Atom


Sublime


HTML


CSS

SASS

NodeJS

PHP


Python


Automator


D3


WordPress


Word


Excel

Illustrator

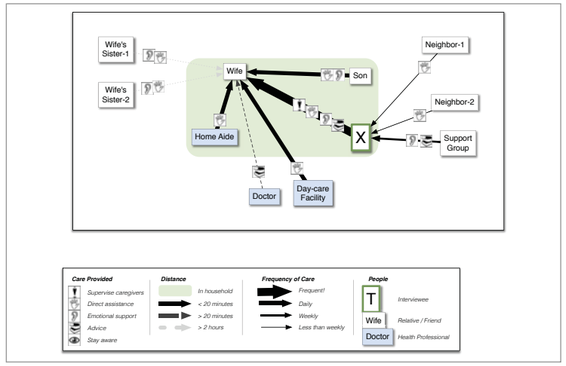
InDesign

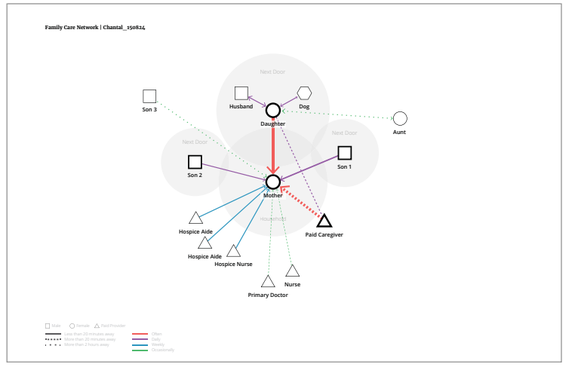
Photoshop

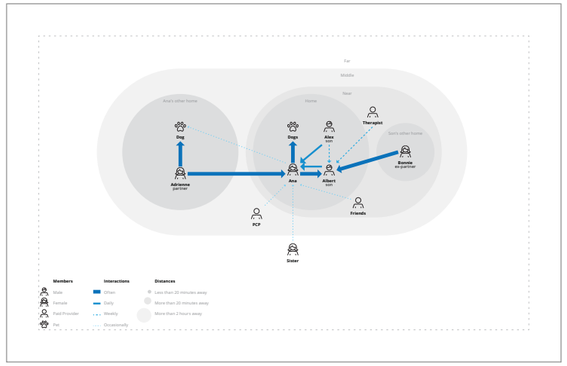
A detailed production matrix let us know where we were in the process.

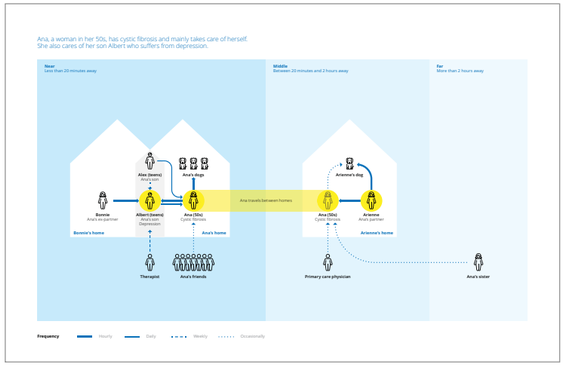
	1 **Ana**	2 **Chantal**	3 **Fay**	4 **Gabrielle**	5 **Hanna**	6 **Gaston**	7 **Harvey**	8 **Fernando**	9 **Laura**	10 **Ida**	11 **Nadine**	12 **Odette**	13 **Nate**	14 **Patty**	15 **Sally**	16 **Tammy**	17 **Rafael**	18 **Teddy**	19 **Omar**	20 **Cindy**
1 **Care Network**	Sketch Draw Design	Sketch Draw Design	Sketch Draw Design	Sketch Draw Design	Sketch Draw Design			Sketch Draw Design		Sketch Draw Design	Sketch Draw Design	Sketch Draw Design	Sketch Draw Design		Sketch Draw Design	Sketch Draw Design		Sketch Draw Design	Sketch Draw Design	
2 **24-hour Log**	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	No data collected	CSV Design Upload to WP Download SVG	No data collected	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG
36-hour Log 3 Broken out 4 Combined	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	No data collected	CSV Design Upload to WP Download SVG	No data collected	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG
Activities 5 Hours spent 6 Minutes spent	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	No data collected	CSV Design Upload to WP Download SVG	No data collected	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG	CSV Design Upload to WP Download SVG
7 **Photo Log**	Design Run script Export SVG	Design Run script Export SVG	Design Run script Export SVG	Design Run script Export SVG	Design Run script Export SVG	Design Run script Export SVG	Design Run script Export SVG	Design Run script Export SVG	Design Run script Export SVG	Design Run script Export SVG	Design Run script Export SVG	Design Run script Export SVG	Design Run script Export SVG	Design Run script Export SVG	Design Run script Export SVG	Design Run script Export SVG (+ Wanda's room)	Design Run script Export SVG	Design Run script Export SVG	Design Run script Export SVG	Design Run script Export SVG
Body 8 EDA 9 Heart Rate 10 Movement	CSV Design Process in MatLab	CSV Design Process in MatLab	CSV Design Process in MatLab	CSV Design Process in MatLab	CSV Design Process in MatLab	CSV Design Process in MatLab	CSV Design Process in MatLab	CSV Design Process in MatLab	No data collected	CSV Design Process in MatLab	CSV Design Process in MatLab	CSV Design Process in MatLab	CSV Design Process in MatLab	CSV Design Process in MatLab	CSV (3 files) Design Process in MatLab	CSV Design Process in MatLab	CSV Design Process in MatLab	CSV Design Process in MatLab	CSV Design Process in MatLab	CSV (battery died) Design Process in MatLab
Environment 11 CO2 12 Humidity 13 Noise	No data collected	Data in DD Design Download SVG	Data in DD Design Download SVG	Data in DD Design Download SVG	No data collected (unknown technical problems)			No data collected		Data in DD Design Download SVG	Data in DD Design Download SVG	Data in DD Design Download SVG	Data in DD Design Download SVG		No data collected	Data in DD Design Download SVG		No data collected	No data collected	
Motion 14 Motion 15 Floorplan	No data collected No floorplan	Data in DD Design Download SVG Floorplan	Data in DD Design Download SVG Floorplan	Data in DD Design Download SVG Floorplan	No data collected No floorplan			No data collected No floorplan		Data in DD Design Download SVG Floorplan	No data collected (hotspot failure?) No floorplan	Data in DD Design Download SVG Floorplan	Data in DD Design Download SVG Floorplan		No data collected No floorplan	Data in DD (only 1 day) Design Download SVG Floorplan		No data collected No floorplan	No data collected No floorplan	
16 **Summary**	Design - 36-hour Log - Body - Environment - Motion	Design - 36-hour Log - Body - Environment - Motion	Design - 36-hour Log - Body - Environment - Motion	Design - 36-hour Log - Body - Environment - Motion	Design - 36-hour Log - Body - Environment - Motion	Design - 36-hour Log - Body - Environment - Motion	Design - 36-hour Log - Body - Environment - Motion (insufficient data)	Design - 36-hour Log - Body - Environment - Motion	Design - 36-hour Log - Body - Environment - Motion (insufficient data)	Design - 36-hour Log - Body - Environment - Motion	Design - 36-hour Log - Body - Environment - Motion	Design - 36-hour Log - Body - Environment - Motion	Design - 36-hour Log - Body - Environment - Motion	Design - 36-hour Log - Body - Environment - Motion	Design - 36-hour Log - Body - Environment - Motion	Design - 36-hour Log - Body - Environment - Motion	Design - 36-hour Log - Body - Environment - Motion	Design - 36-hour Log - Body - Environment - Motion	Design - 36-hour Log - Body - Environment - Motion	Design - 36-hour Log - Body - Environment - Motion

We iterated and refined the design over the course of the project.

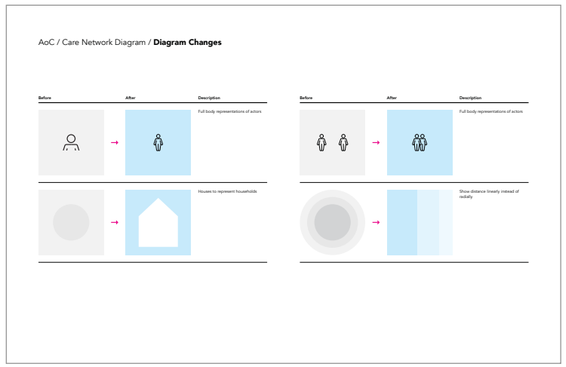


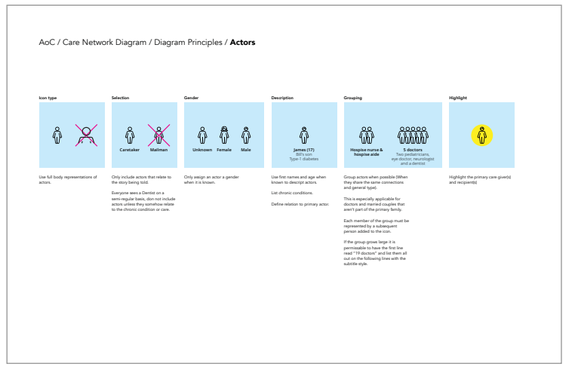


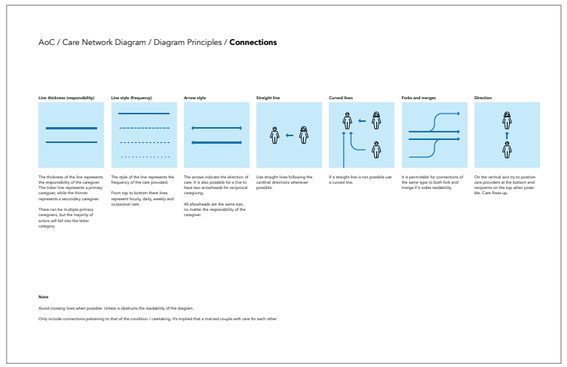




Refinements







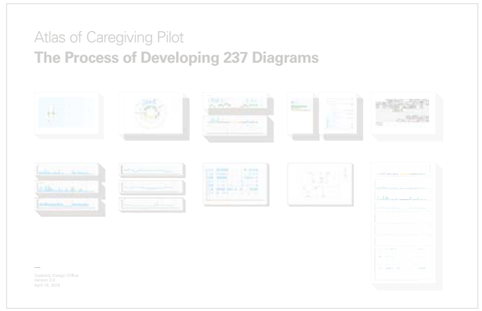
Rationale

We created a design rationale document which explains our decisions.

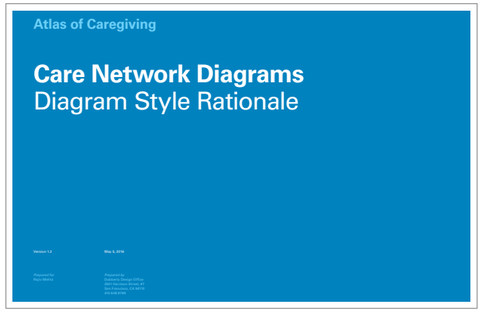
Study Report

Data Visualizations

Diagram Development



Care Network Rationale

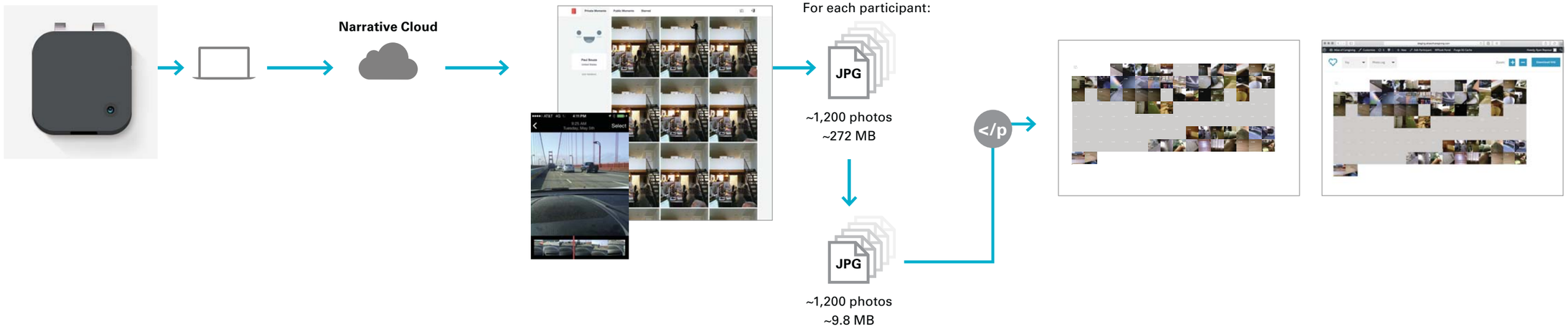


Website

Care Network Rationale posted at http://staging.dubberly.com/atlas/160504-Final_Documents/AoC_Care_Network_Diagram_Style_160505a.pdf

We used D3 (Data Driven Documents) to visualize the hand-written participant logs.

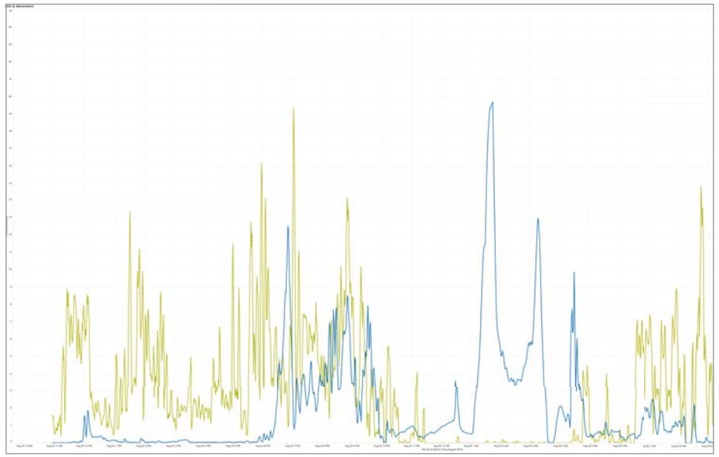
We wrote a script to select a subset of photos and used NodeJS to lay them out in a grid. We also shared our code on GitHub.

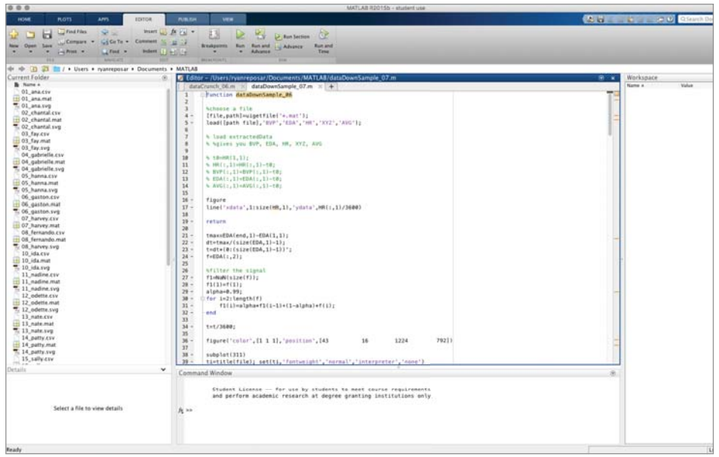


https://github.com/dubberlydesign/photogrid

Many applications—including specialized data visualization tools—could not handle the amount of data collected.

Date & Time	BVP	EDA	HR	x	y	z	moving AVG ACC
2015-08-31 09:50:47	0	0		-12	16	60	
2015-08-31 09:50:47	0						
2015-08-31 09:50:47	0			-12	16	60	
2015-08-31 09:50:47	0						
2015-08-31 09:50:47	0			-12	16	60	
2015-08-31 09:50:47	0						
2015-08-31 09:50:47	0			-11	16	60	
2015-08-31 09:50:47	0						
2015-08-31 09:50:47	0			-11	16	61	
2015-08-31 09:50:47	0						





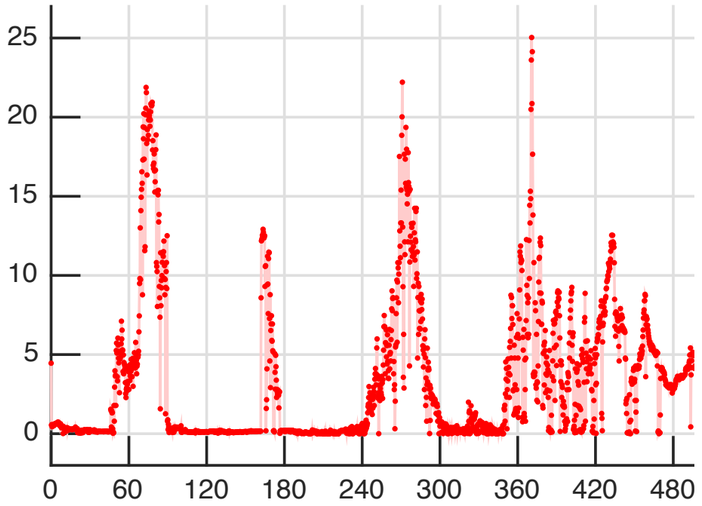
Microsoft Excel could not open all data files, and if it could open, it would crash when we tried to make changes.

Tableau could open the data files, but it didn't offer vector output, which was a design requirement (to enable zooming into SVGs).

MatLab met our needs but required file conversion which took 20 hours (1 hour per participant), and an expert user.

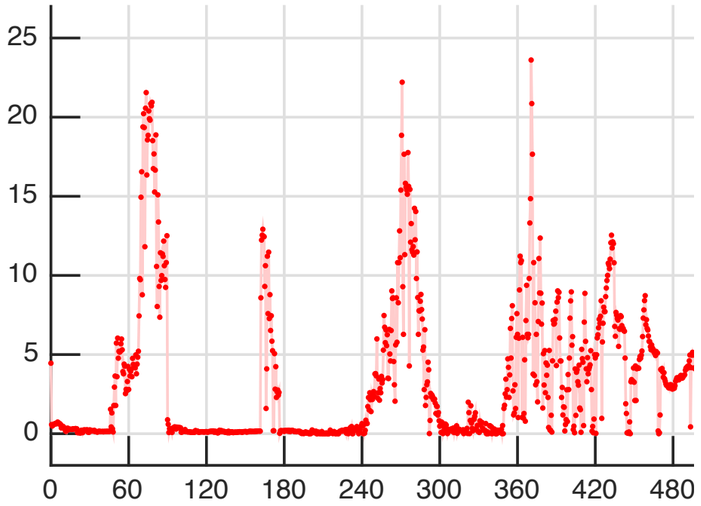
We gathered more data than we could show.

It needed to be downsampled, but how much?



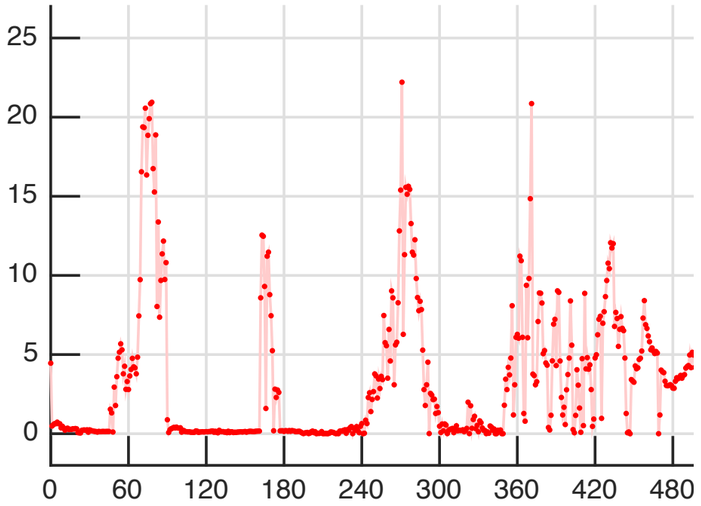
EDA sampled once every 15 seconds

8640 data points



EDA sampled once every 30 seconds

4320 data points



EDA sampled once every 60 seconds

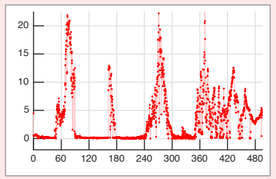
2160 data points

(2160 is 2 × 1080,
a common screen resolution.)

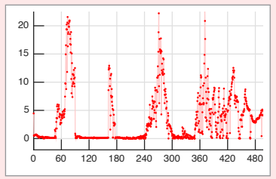
How the diagrams would be presented helped guide our decision.

2 minutes in the data equals 1 point in the diagram.

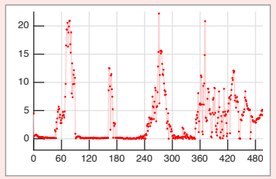
DATA DOWNSAMPLING

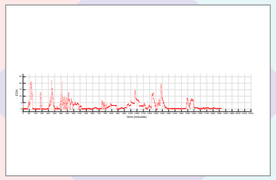


÷2



÷2





8640
data points
1/15 seconds

4320
data points
1/30 seconds

2160
data points
1/60 seconds

is 2× is ½

1080
points
15-inches

=

144
points
1-inch margins

-

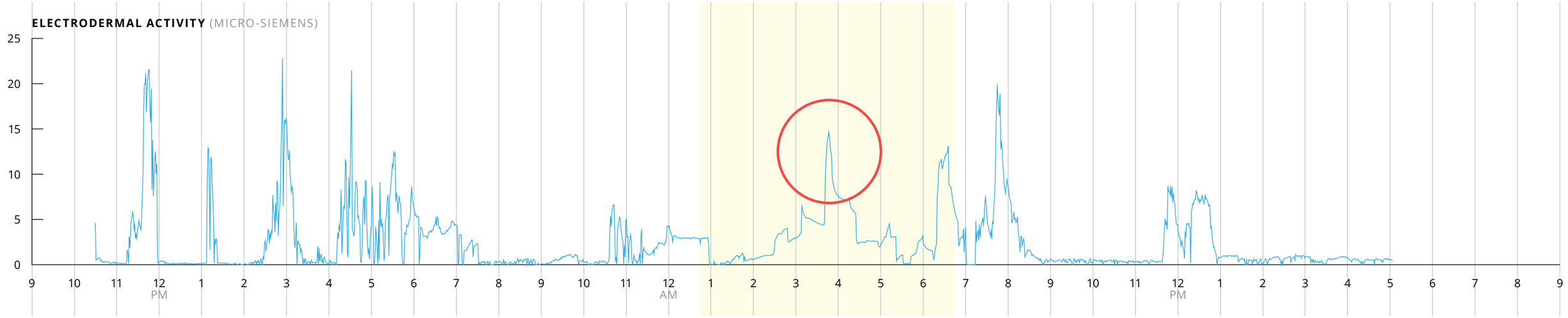
1224
points
17-inches

PRESENTATION AREA

EDA data spiked unexpectedly in the middle of the night.

Was the participant stressed in a lucid dream?

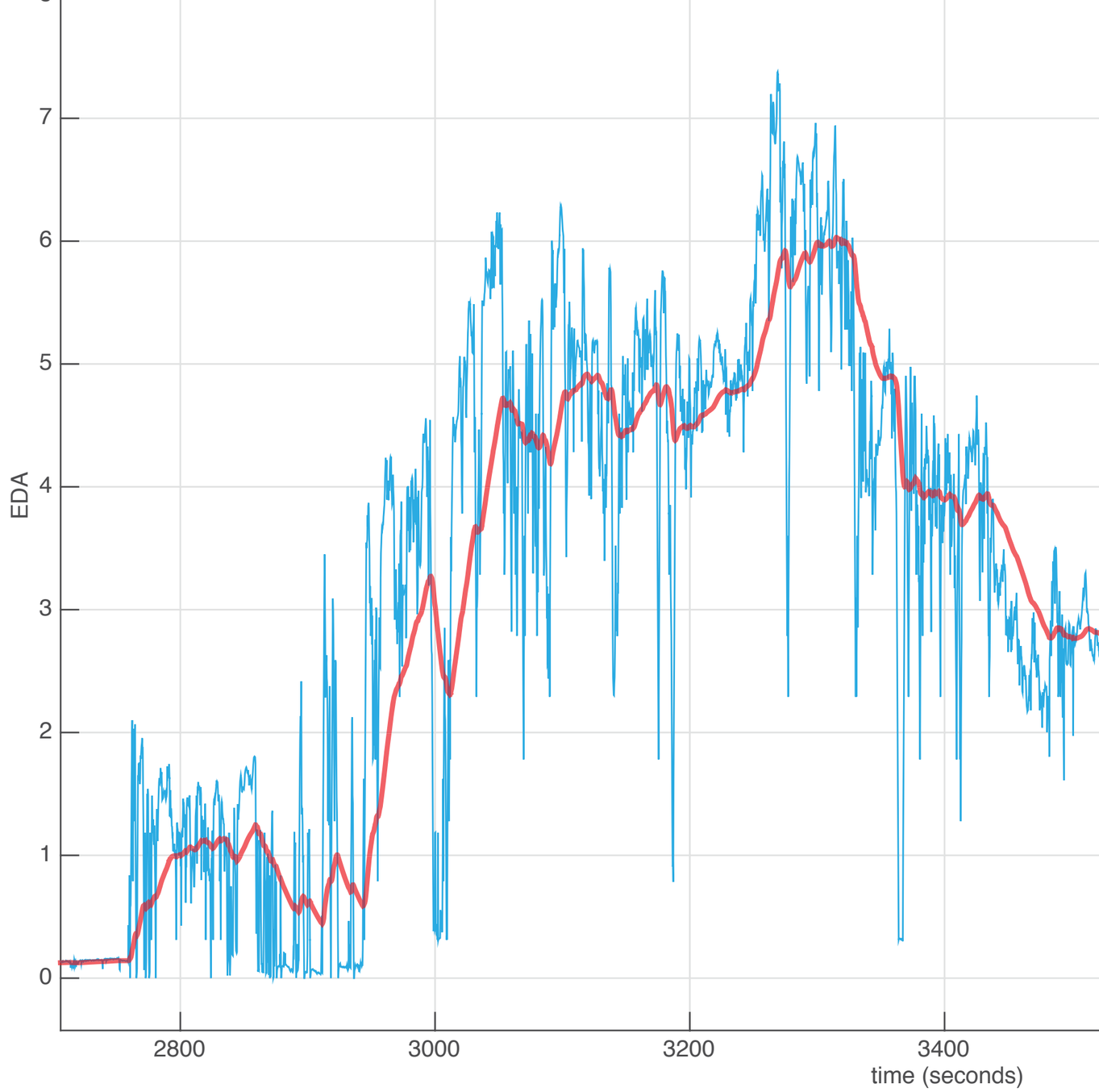
Or did they simply get too hot under their blankets?



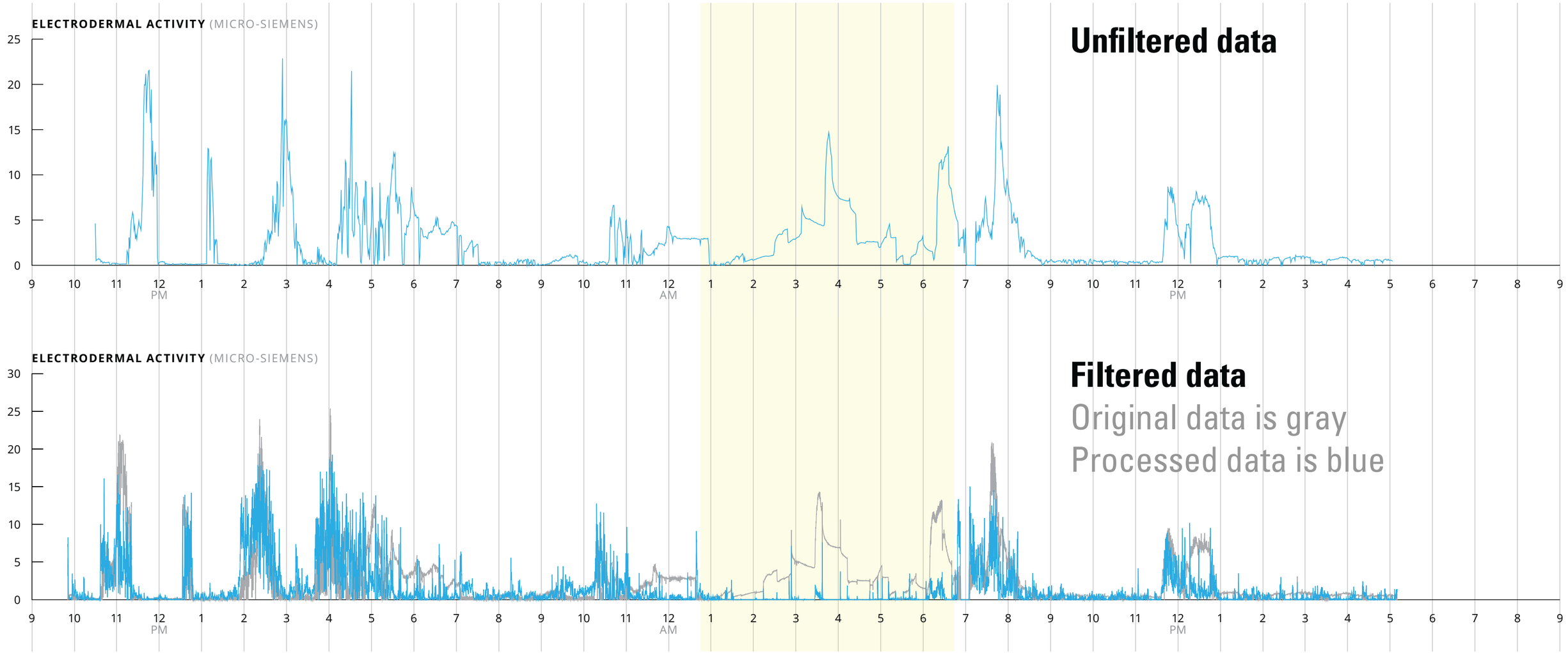
The spike would have to be removed, but how?

In the context of EDA data, "slow" (tonic) and "fast" (phasic) seem to refer to a slow moving baseline, and then fluctuations around that baseline.

We ran a transform on the data which looked for rapid fluctuations and smoothed them out.

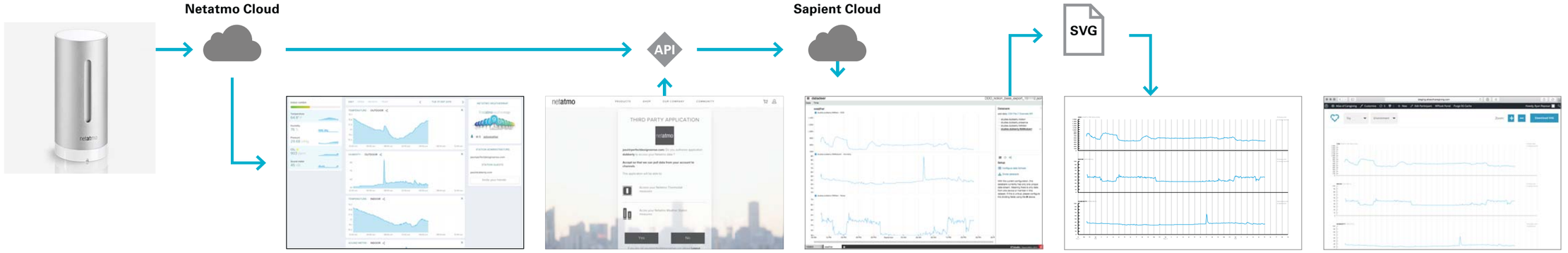


Comparison of the original, unfiltered data, with the final, filtered data.



Manufacturer's software could be even more powerful.

Sapient gave us access to more powerful tools they've developed.



PART FIVE

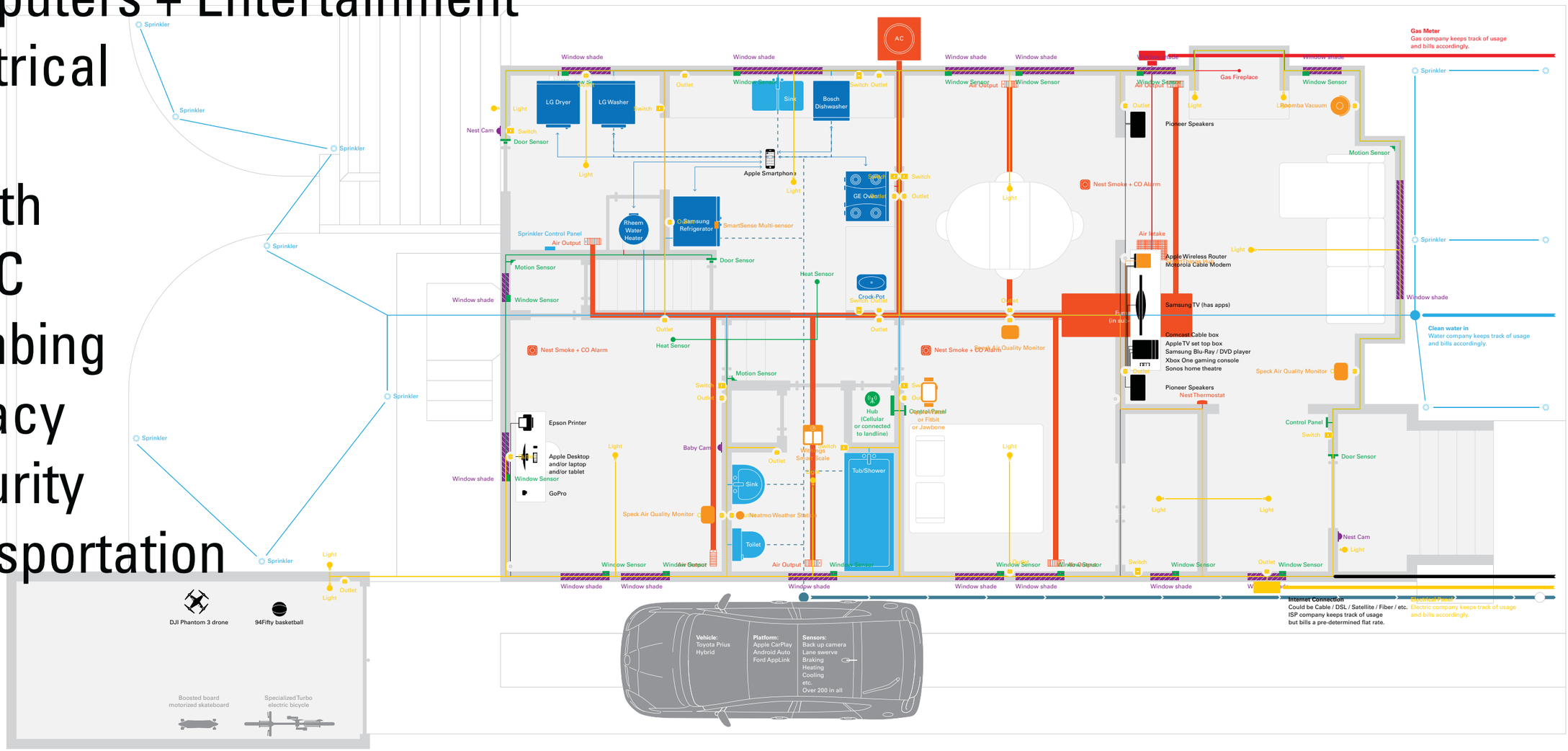
Results:
What did we learn?

Conclusions

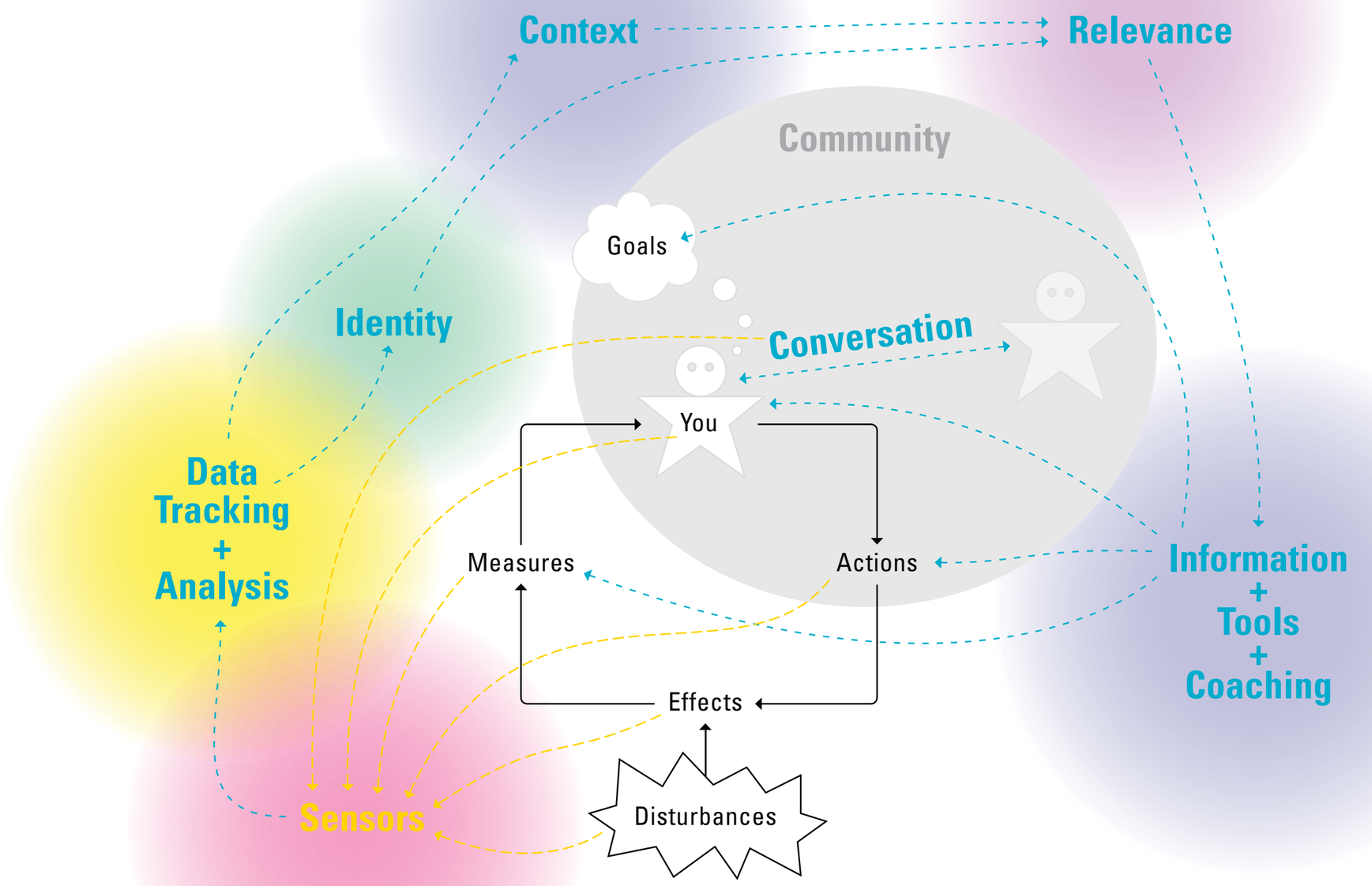
- Special sensors can measure stress in lab settings and in highly controlled studies; however, even the very best consumer devices do not yet provide useful stress data in uncontrolled general use—though opportunities for correlating stress and other data abound.
- Off-the-shelf sensors are here, but processing the data requires special knowledge of specialized tools.
- Healthcare—and the rest of our lives—are about to experience an explosion of sensor-generated data.

IoT devices in homes will produce and collect massive amounts of data:

- Appliances
- Computers + Entertainment
- Electrical
- Gas
- Health
- HVAC
- Plumbing
- Privacy
- Security
- Transportation



Sensors will be ubiquitous: at checkpoints, logging everything you do online, all around you, on you, and in you.



What does this mean? Massive data collecting—organized into a taxonomy of personal identity

Drilling into a sub-categories shows the potential for detail;

Today lab tests can measure over 150 analytes; more tests are in development.

Wellbeing

Grooming + Prevention

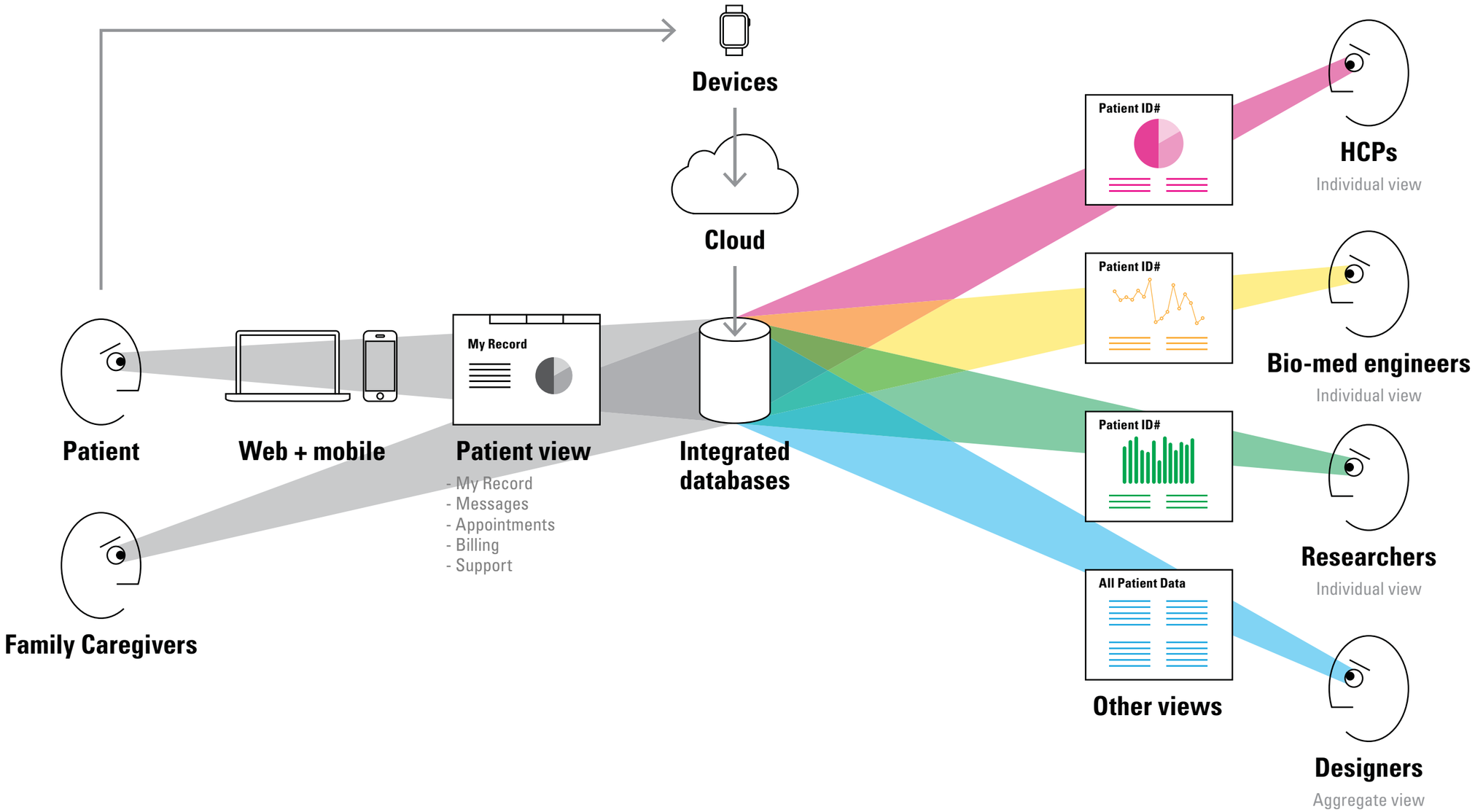
Body Systems

Emotions + Affect

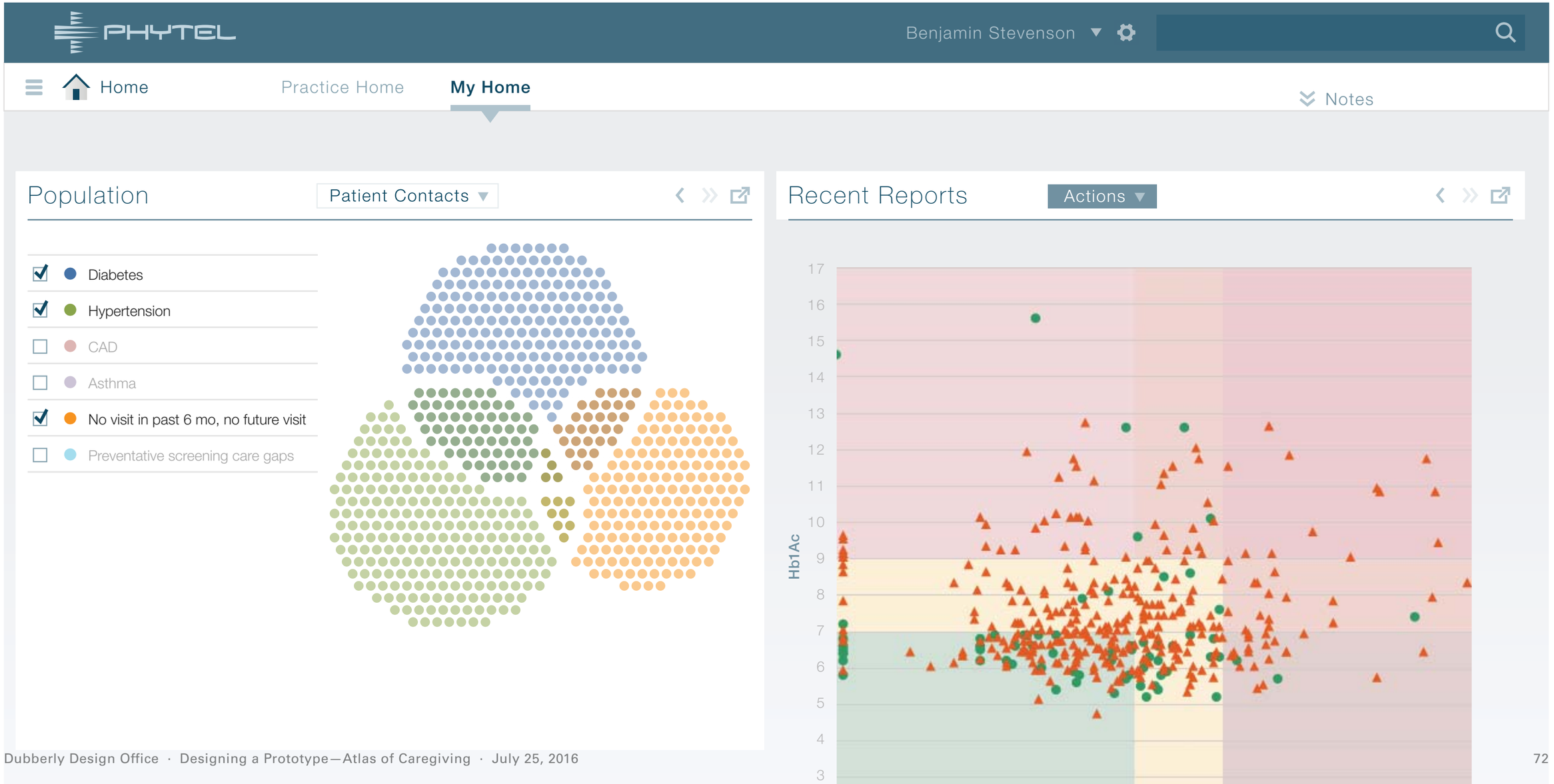
Exercises + Diet

		(hydrocortisone)	Normal, PM: 3–17 µg/dL
		17 Hydroxyprogesterone * See also: ovaries	Man, normal: .06–3 mg/L Woman (follicular phase), normal: .2–1 mg/L
		Angiotensin-converting enzyme (ACE)	Normal: 23–57 U/L
	Pituitary gland	Growth hormone	At peak: 5–45 ng/mL Between peaks: < 5 ng/mL
		Follicle-stimulating hormone (FSH)	Prepubertal: < 1 – 3 IU/L Adult male: 1–8 IU/L Adult female (follicular & luteal phase): 1–11 IU/L Adult female (ovulation): 6–26 IU/L Post-menopausal female: 30–118 IU/L
		Adrenocorticotropic hormone (ACTH)	Normal: 20–80 pg/mL
		Prolactin	Female, normal: < 20 ng/mL Male, normal: < 15 ng/mL
Cardiovascular	Blood	Blood Glucose	Hypoglycemia: < 3 mmol/l Normal: 3.6–5.8 mmol/l Normal, post-meal: <10 mmol/l Hyperglycemia: > 7 mmol/l (chronically)
		Luteinizing hormone (LH)	Female (peak): 20–75 IU/L emale (post-menopausal): 15–60 IU/L
		Insulin absorption	-
		Plasma osmolality	Normal: 275–295 mOsm/kg
	Blood: lipids	Total cholesterol	Desirable: < 200

Unified patient and device data will afford useful views to many constituents.



New machine learning systems will look for patterns, identify signals of risk, and warn patients and caregivers of impending problems.

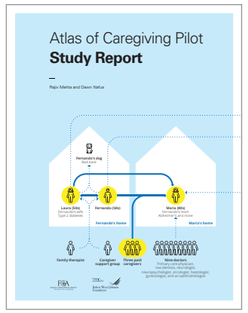


Looking to the future

- New IoT devices, including robots, are entering the home and medical markets.
- These devices, plus a new generation of more precise sensors suggest potential for a follow up study.
- Increasingly sensors will detect bio-markers leading to more personalized medicine.
- Over the next several years, IoT devices and sensors will become an integral part of healthcare—especially managed care. And managed care organizations will become increasingly concerned about family caregiving.

All the documents mentioned in this talk are available online.

Study Report



Data Visualizations

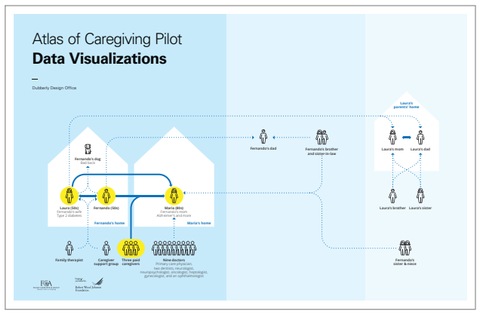
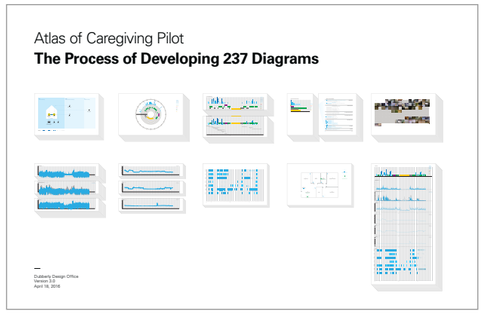
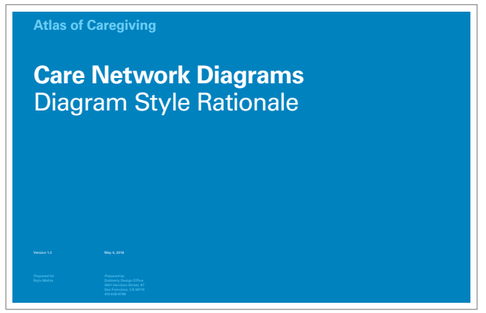


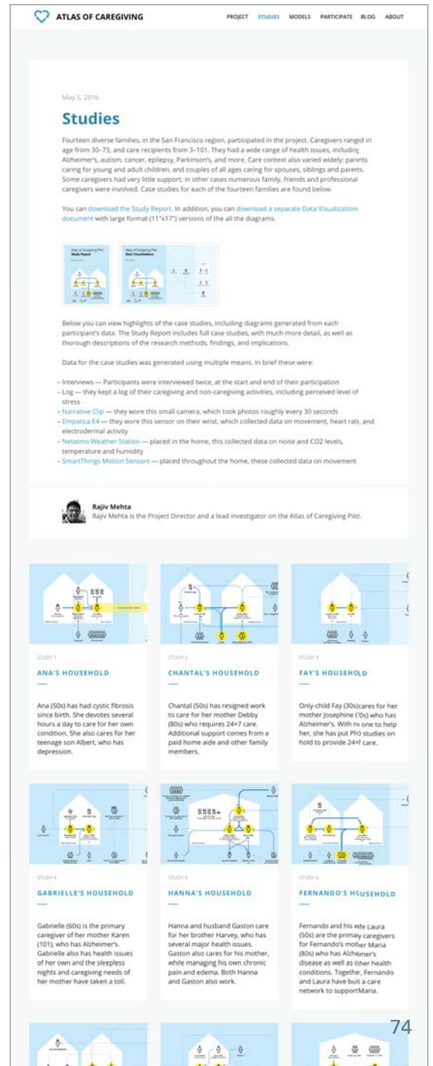
Diagram Development



Care Network Rationale



Website



Study Report posted at http://atlasofcaregiving.com/wp-content/uploads/2016/03/Study_Report.pdf
Data Visualizations posted at http://atlasofcaregiving.com/wp-content/uploads/2016/03/Data_Visualizations.pdf
Diagram Development posted at http://staging.dubberly.com/atlas/160504-Final_Documents/AoC_Development_160505a.pdf
Care Network Rationale posted at http://staging.dubberly.com/atlas/160504-Final_Documents/AoC_Care_Network_Diagram_Style_160505a.pdf
Learn more about the project at http://atlasofcaregiving.com

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