

The Possibilities of Digital and Analogue Technology in Parkinson's



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Symptom Knowledge in Parkinson's *(digital)*

Previous work

Most approaches have been

- Uncomfortable
- Disruptive
- Motor oriented
- Using a single device



Missing potential

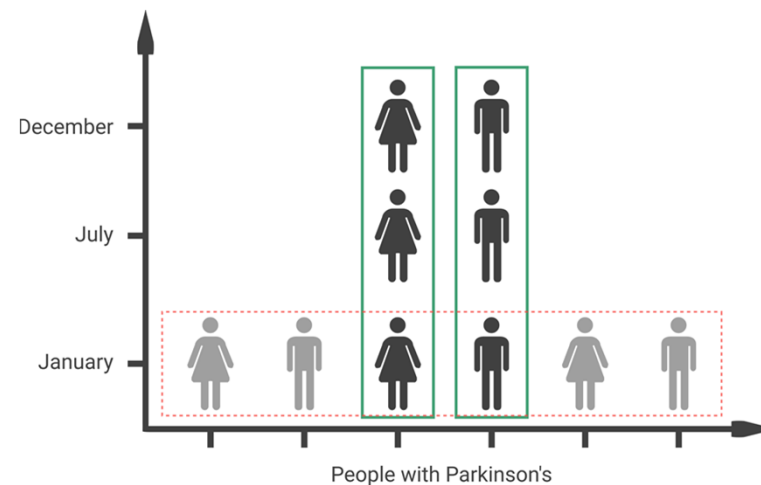
Consumer electronics can be **heterogeneous (mixed)** data sources

Personal	Environmental	Web
Movement	Infrared	Weather
Smartphones	Pressure	Social Networks
Wearables	Video	Geographic data

What is new in SKIP?

Combine heterogeneous sources to allow an assessment that is:

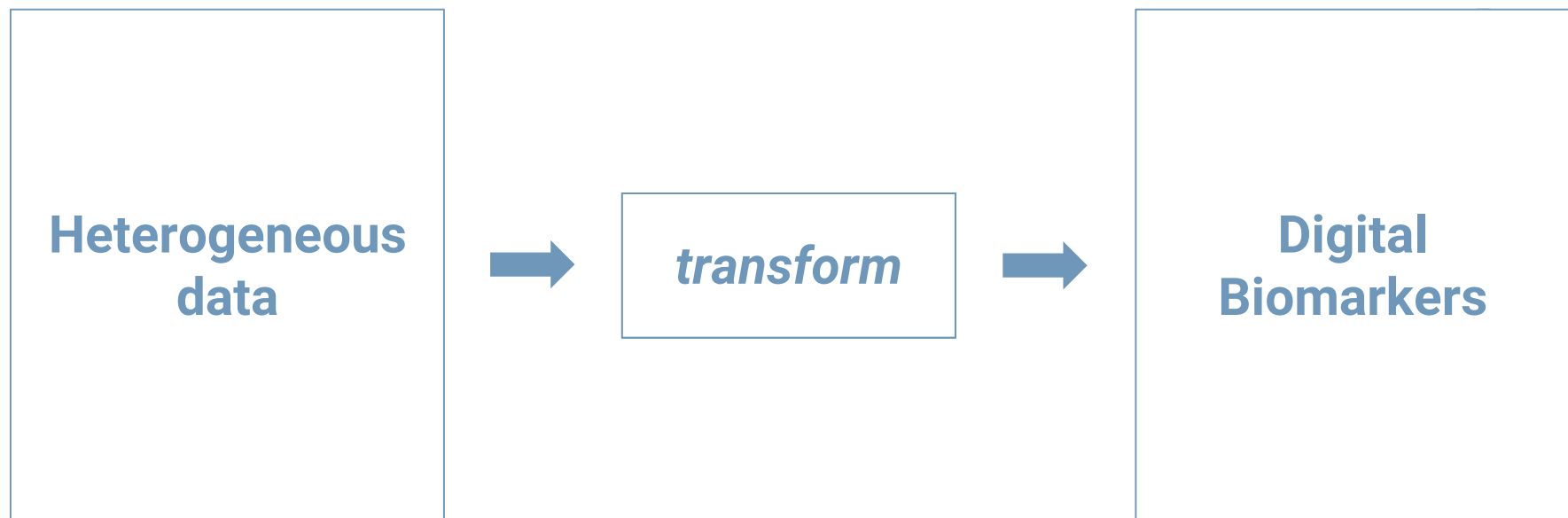
- Continuous
- Longitudinal
- Naturalistic
- **Unobtrusive**
- **Personalised**



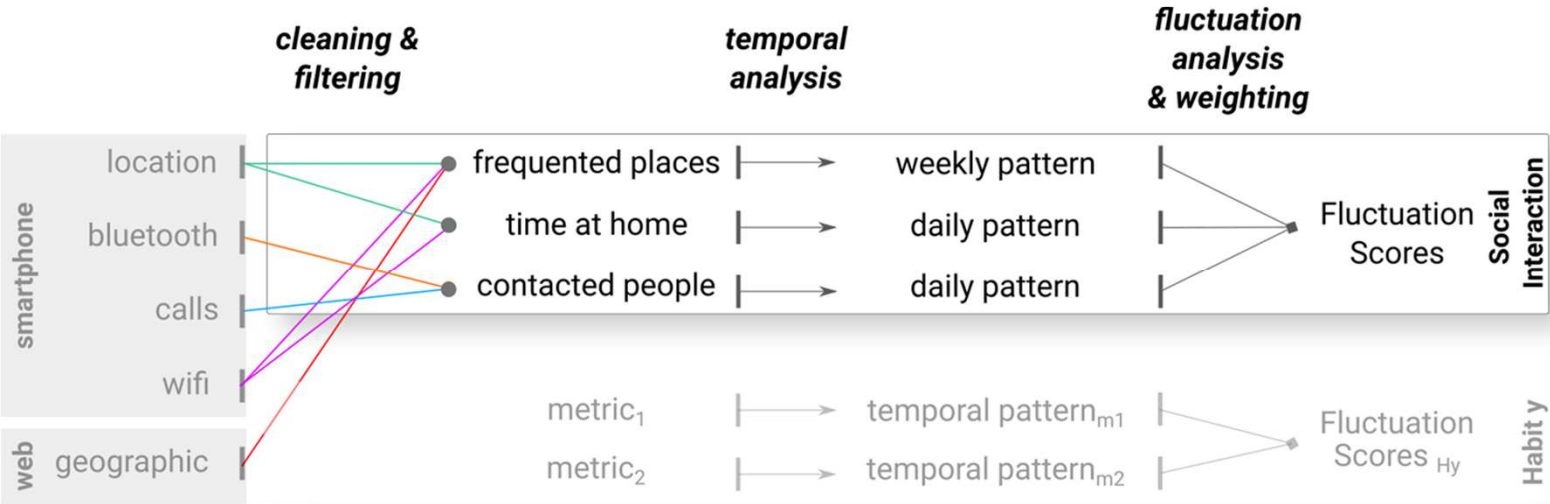
Our goal is to *reconstruct* people's daily routines



Methodology

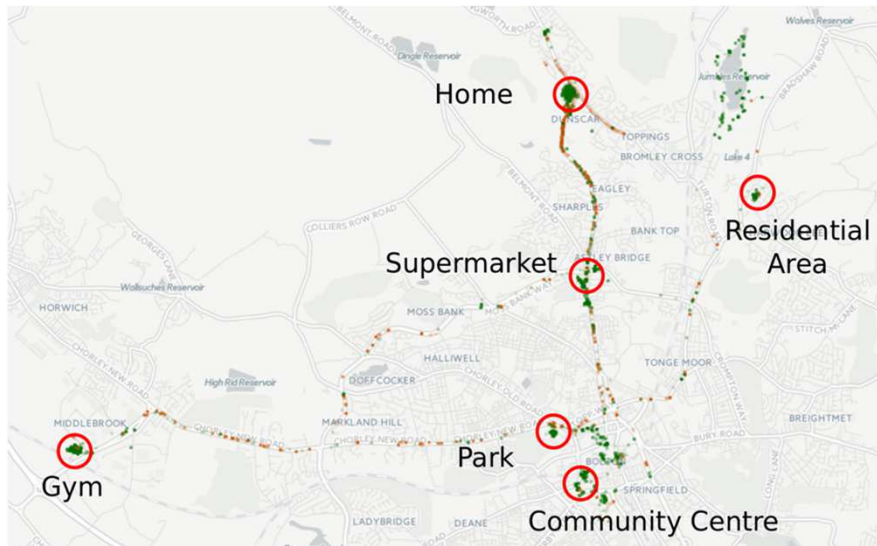


Profile of Living

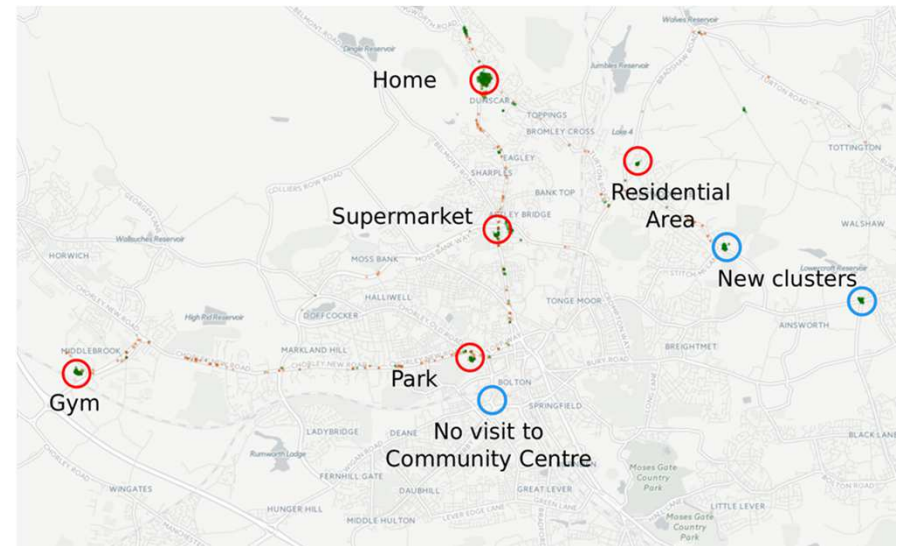


Digital Biomarkers Examples

Visited places

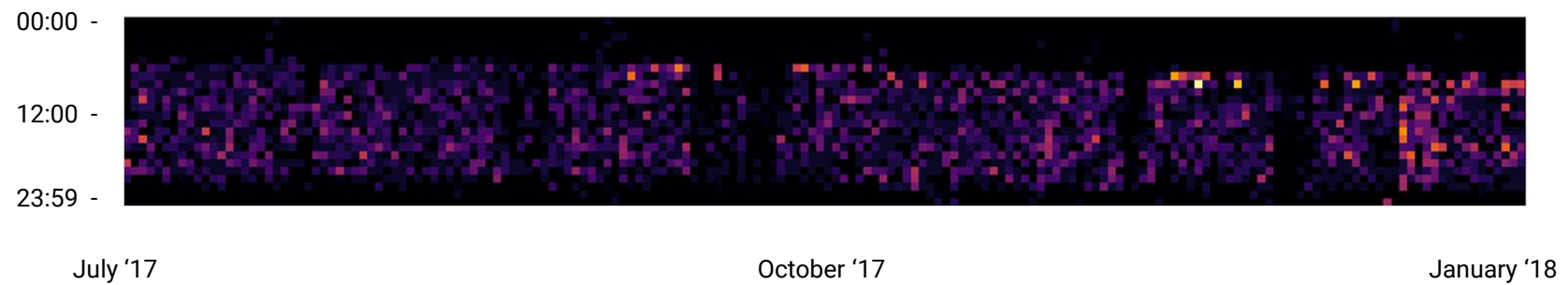


day 01 - 15



day 16 - 30

Phone usage



Current work

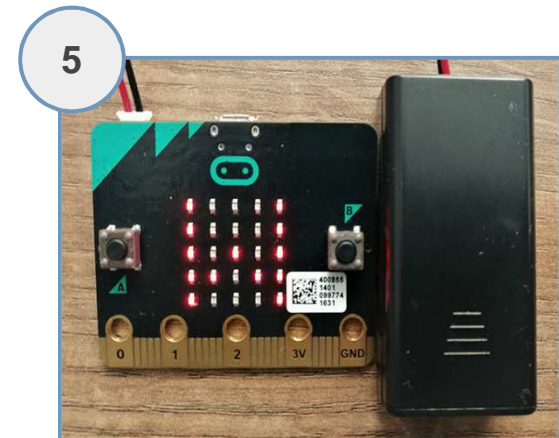
We are running a **9-month study**

- Monitoring 11 people, 24/7
- Collecting up to 22 different data sources using Android and iOS smartphones as main device
- Visiting participants every six weeks to collect ground truth

And Analogue...



Agile Prototyping



Paper Diary

- Flexible
- Personalised
- No handwriting required
- Blending digital/analogue
- Open source
- **97% compliance**

6

So far, what is the severity of your symptoms?

HH MM Low Energy None O O O High

11 12 1 00

10 am 2 15 Sleep None O O O High

9 pm 3 30 Attention None O O O High

8 7 6 5 45

Optional

HH MM Low Energy None O O O High

11 12 1 00

10 am 2 15 Sleep None O O O High

9 pm 3 30 Attention None O O O High

8 7 6 5 45

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Please, fill out at least one row per day SKIP

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Time

Severity

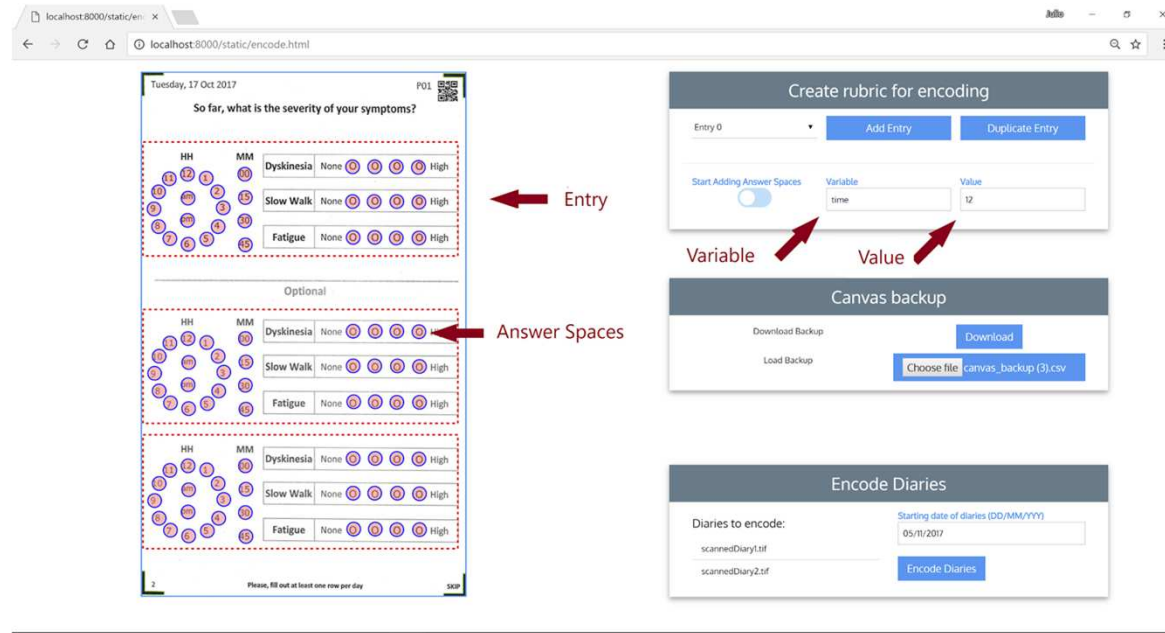
Symptoms

Design implications

1. Reduce participant **completion demand**
2. Design to offset the **effect of tremor** on input
3. Enable **implicit reminders**
4. Design for consequences of **increased awareness**
5. Consider the **effects of handwritten notes** in compliance, encoding burden and data quality

Published in CHI'18: bit.do/paper_diary

PaperStream



You can use PaperStream to create and encode diaries/surveys for free
bit.do/pstream

Key messages

Design **for and with** People with Parkinson's

Aim for **unobtrusive and personalised**

Consider **analogue** approaches

Thank you!

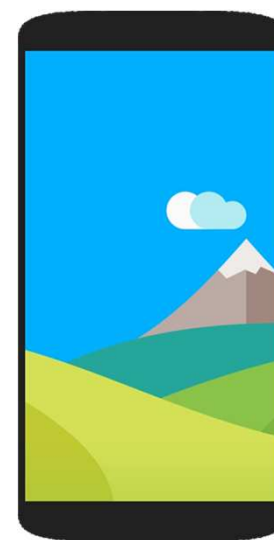
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First efforts

- Interviews with clinicians and neuroscientists
- Focus groups with *people with Parkinson's*
- Pilot study monitoring 2 people, 24/7 for 3 months using a smartphone

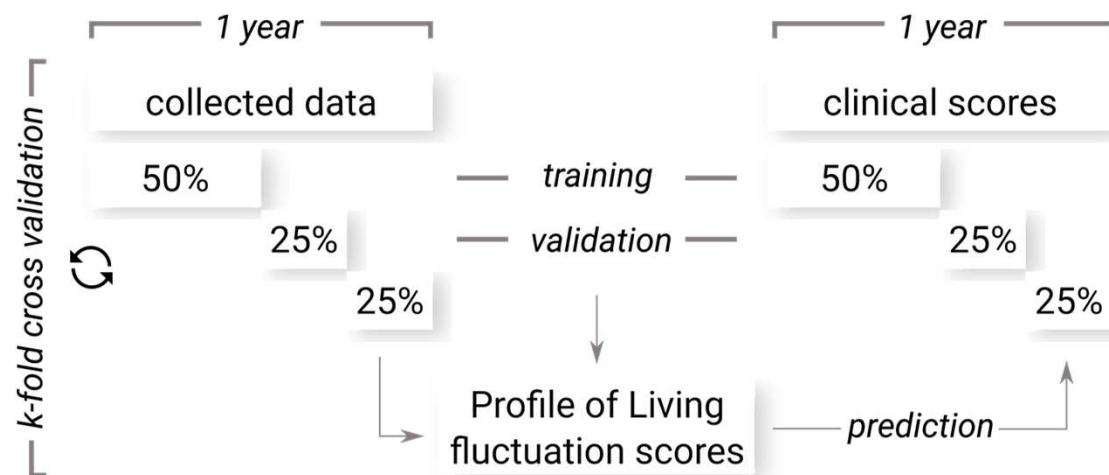


Call log

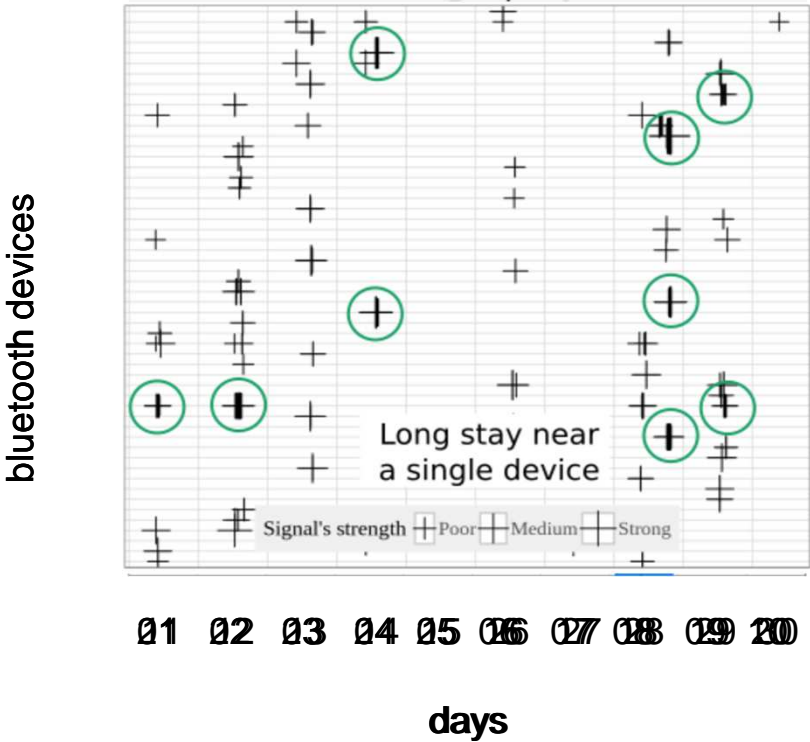


Evaluation

Predict **clinical scores** based on **fluctuation scores**



Bluetooth profiling



Problem

1. Parkinson's is **neuro-degenerative** and incurable
2. Symptoms are many and **fluctuate** daily
3. Patients visit their clinicians **twice a year**



Emotional



Motor



Cognitive

Goals

Is it possible to:

1. **Infer** complex human behaviour from heterogeneous data?
2. **Measure** the influence of Parkinson's on the inferred behaviour?
3. **Monitor** Parkinson's progression using the fluctuations of such behaviour?

Metrics to explore

Digital Biomarker	Metric
Social Interaction	<ol style="list-style-type: none">1. Time at home2. Visited places (frequency, duration)3. Duration & frequency of calls and texts4. Profiling of Bluetooth devices
Phone use	<ol style="list-style-type: none">1. Get-up time2. Bed time3. Typing patterns4. Use sessions at day and night