# The Ubiquitous Health Technology Lab

## Advancing the Role of IoT in Public Health Research

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University Health Network

UBILAB

Centre for Global eHealth Innovation University Health Network



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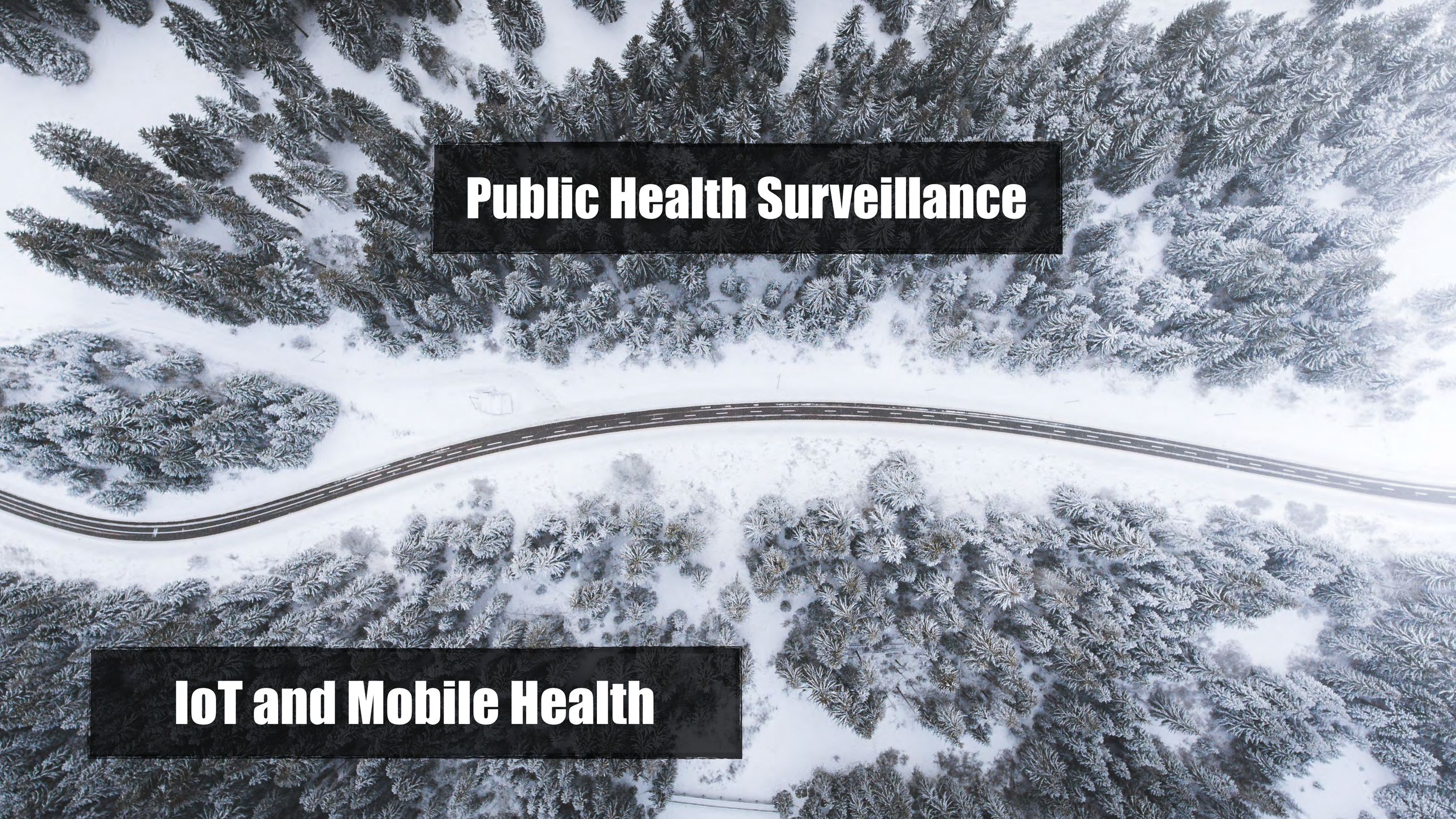
# UBILAB

UBIQUITOUS HEALTH TECHNOLOGY LAB

# The Ubiquitous Health Technology Lab (UbiLab)



# Public Health Surveillance

# IoT and Mobile Health

# EXTREME COLD

# EXTREME HEAT

# EXTREME AIR POLLUTION

# PANDEMICS

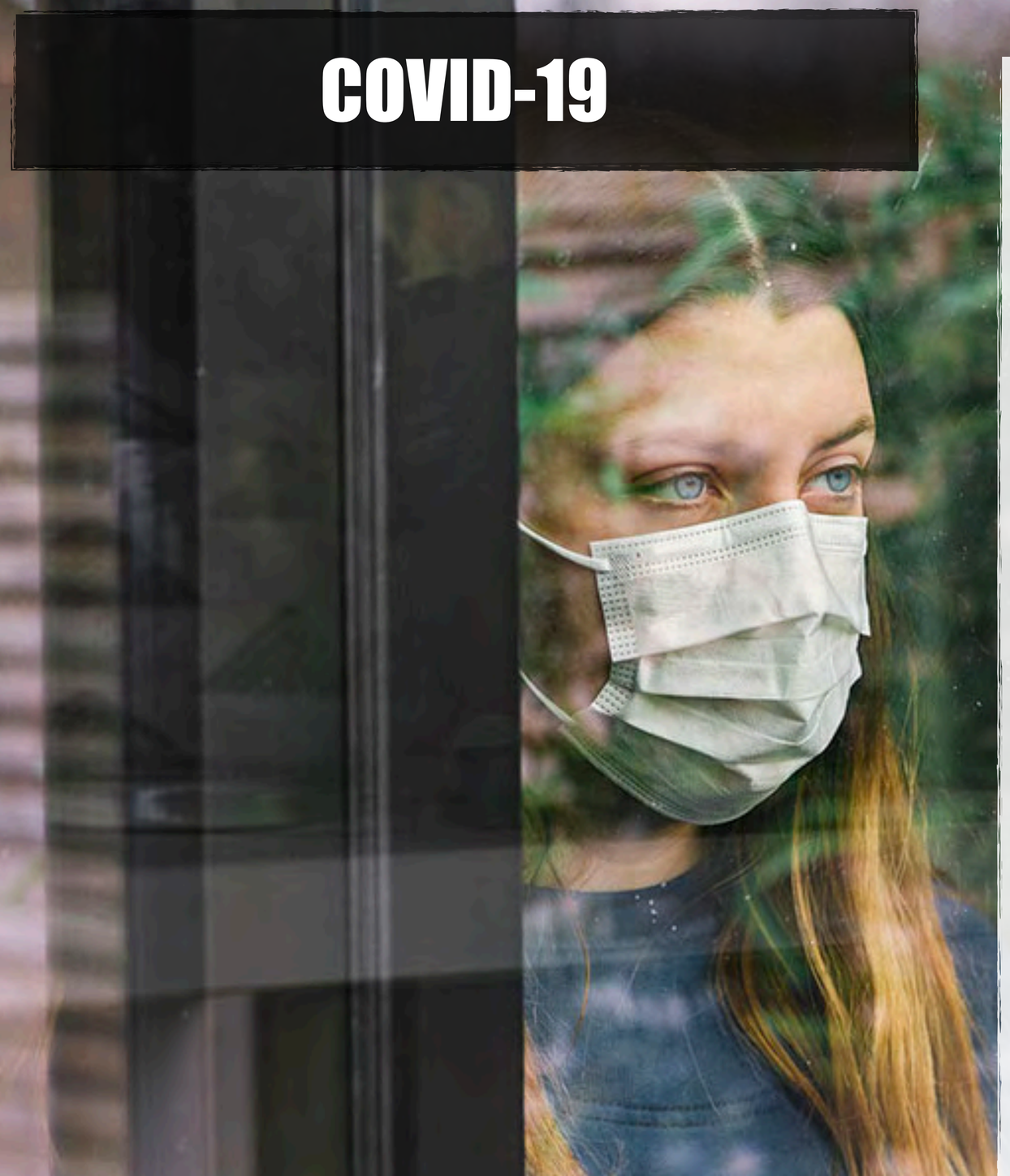
# PUBLIC HEALTH SURVEILLANCE

# Wearables

# Internet of Things

# THE HIDDEN IMPACT OF THE COVID-19 PANDEMIC

# COVID-19



Position Paper

# Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science

*Emily A Holmes*, Rory C O'Connor*, V Hugh Perry, Irene Tracey, Simon Wessely, Louise Arseneault, Clive Ballard, Helen Christensen, Roxane Cohen Silver, Ian Everall, Tamsin Ford, Ann John, Thomas Kabir, Kate King, Ira Madan, Susan Michie, Andrew K Przybylski, Roz Shafran, Angela Sweeney, Carol M Worthman, Lucy Yardley, Katherine Cowan, Claire Cope, Matthew Hotopf†, Ed Bullmore†*

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**The coronavirus disease 2019 (COVID-19) pandemic is having a profound effect on all aspects of society, including mental health and physical health. We explore the psychological, social, and neuroscientific effects of COVID-19 and set out the immediate priorities and longer-term strategies for mental health science research. These priorities were informed by surveys of the public and an expert panel convened by the UK Academy of Medical Sciences and the mental health research charity, MQ: Transforming Mental Health, in the first weeks of the pandemic in the UK in March, 2020. We urge UK research funding agencies to work with researchers, people with lived experience, and others to establish a high level coordination group to ensure that these research priorities are addressed, and to allow new ones to be identified over time. The need to maintain high-quality research standards is imperative. International collaboration and a global perspective will be beneficial. An immediate priority is collecting high-quality data on the mental health effects of the COVID-19 pandemic across the whole population and vulnerable groups, and on brain function, cognition, and mental health of patients with COVID-19. There is an urgent need for research to address how mental health consequences for vulnerable groups can be mitigated under pandemic conditions, and on the impact of repeated media consumption and health messaging around COVID-19. Discovery, evaluation, and refinement of mechanistically driven interventions to address the psychological, social, and neuroscientific aspects of the pandemic are required. Rising to this challenge will require integration across disciplines and sectors, and should be done together with people with lived experience. New funding will be required to meet these priorities, and it can be efficiently leveraged by the UK's world-leading infrastructure. This Position Paper provides a strategy that may be both adapted for, and integrated with, research efforts in other countries.**

## Introduction

It is already evident that the direct and indirect psychological and social effects of the coronavirus disease 2019 (COVID-19) pandemic are pervasive and could affect mental health now and in the future. The pandemic is occurring against the backdrop of increased prevalence of mental health issues in the UK in recent years in some groups.[1,2] Furthermore, severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), the virus that causes COVID-19, might infect the brain or trigger immune responses that have additional adverse effects on brain function and mental health in patients with COVID-19.

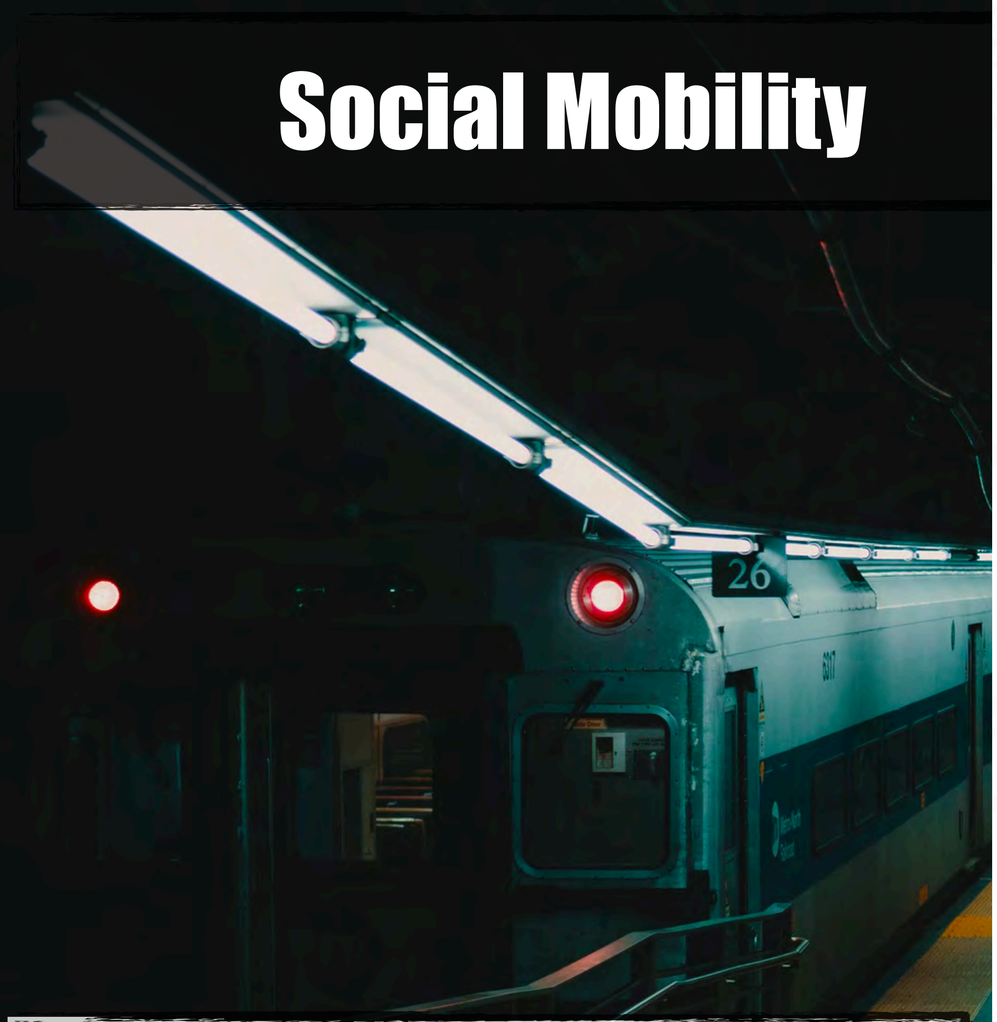
Research funders and researchers must deploy resources to understand the psychological, social, and neuroscientific effects of the COVID-19 pandemic. Mobilisation now will allow us to apply the learnings gained to any future periods of increased infection and lockdown, which will be particularly important for front-line workers and for vulnerable groups, and to future pandemics. We propose a framework for the prioritisation and coordination of essential, policy-relevant psychological, social, and neuroscientific research, to ensure that any investment is efficiently targeted to the crucial mental health science questions as the pandemic unfolds. We use the term mental health sciences to reflect the many different lived experience of mental health issues or COVID-19 to address these research priorities.

The UK has powerful advantages in mounting a successful response to the pandemic, including strong existing research infrastructure and expertise, but the research community must act rapidly and collaboratively if it is to deal with the growing threats to mental health. A fragmented research response, characterised by small-scale and localised initiatives, will not yield the clear insights necessary to guide policy makers or the public. Rigorous scientific and ethical review of protocols and results remains the cornerstone of safeguarding patients and upholding research standards. Deploying a mental health science perspective[3] to the pandemic will also inform population-level behaviour change initiatives aimed at reducing the spread of the virus. International comparisons will be especially helpful in this regard. In this Position Paper, we explore the psychological, social, and neuroscientific effects of COVID-19 and set out clear immediate priorities and longer-term strategies for each of these aspects.

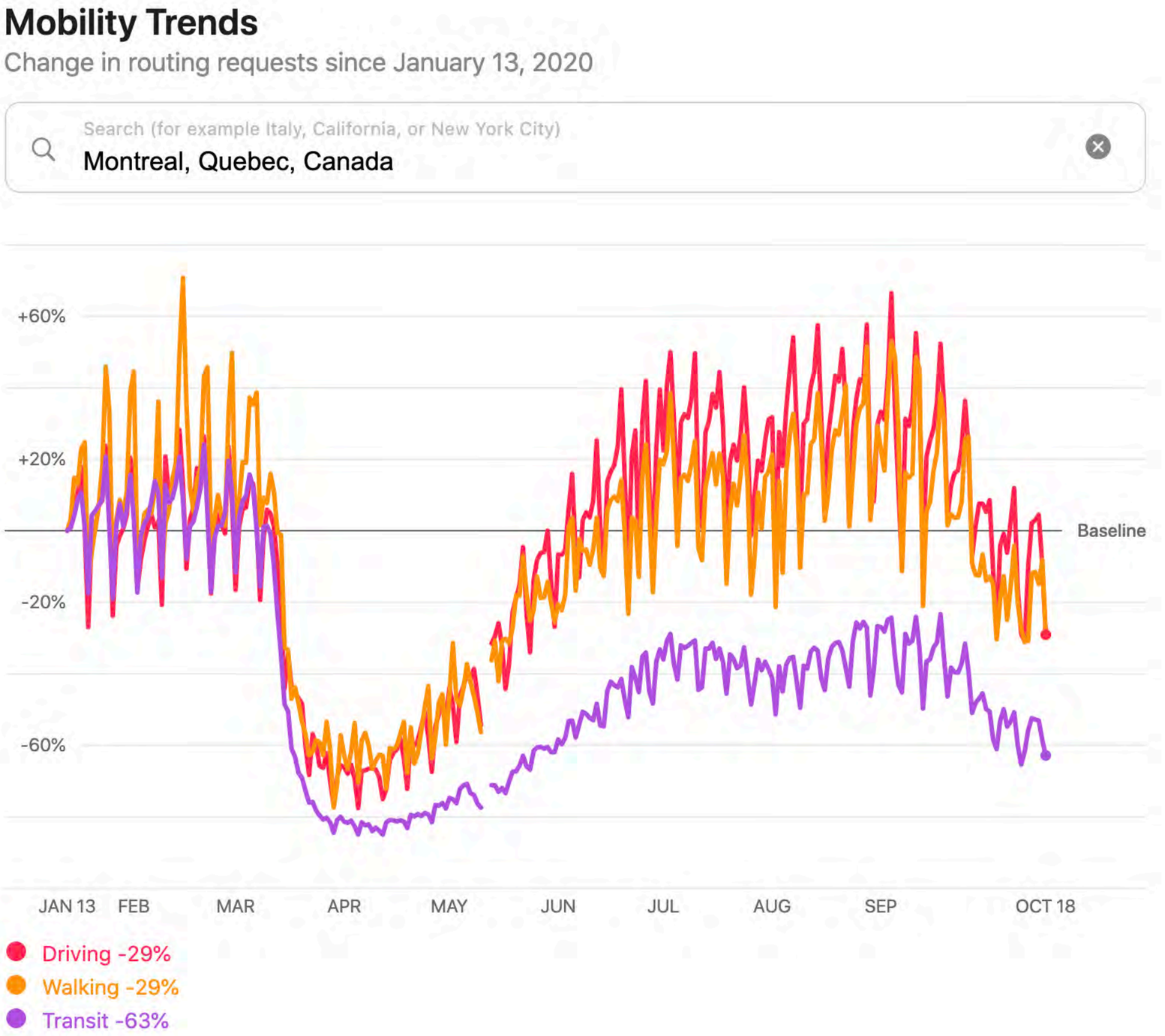
We also surveyed the public and people with lived experience of mental ill-health (panel 1). The general population survey, done by Ipsos MORI,[4] revealed widespread concerns about the effect of social isolation or social distancing on wellbeing: increased anxiety

# Working from Home

# Social Mobility




Stevens, N., Kiwon, F., Morita, P.P., Sen., A., and Steiner, S. Predicting Daily COVID-19 Cases Using Google Mobility Data: Evidence from Canadian Provinces. *Canadian Public Policy*, 2021, In review.



# UNDERSTANDING THE IMPACT OF COVID-19

FITBIT NEWS APRIL 2, 2020

# The Impact Of COVID-19 On Global Sleep Patterns

BY FITBIT STAFF

Last week, we shared an important story about the impact COVID-19 has had on our global Fitbit community's physical activity levels and provided a few tips on how we can help. This week, we've taken a look at how sleep patterns have changed during this time. Based on our review of aggregated and anonymized data, we saw that in locations with shelter-in-place mandates, bedtime and bedtime consistency shifted.

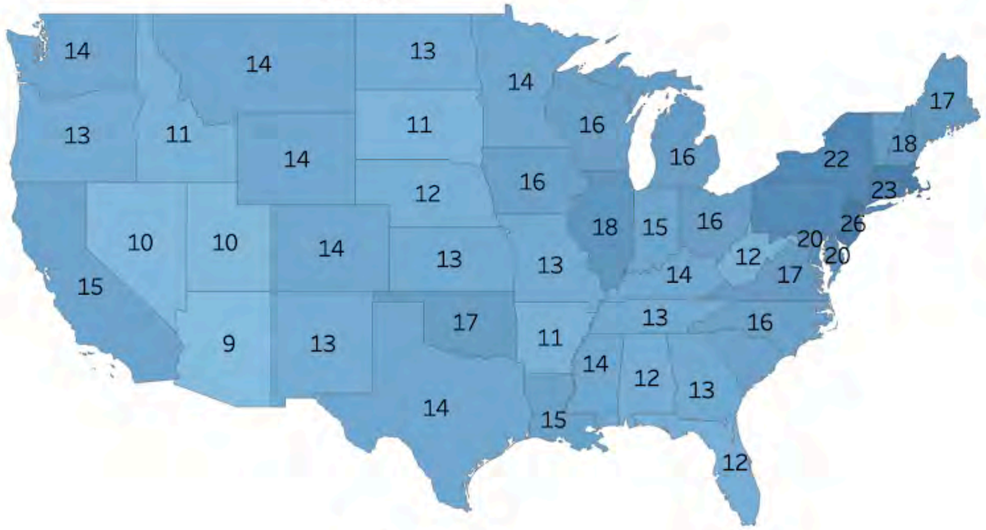
For the most part, people are going to bed later but getting more sleep, as well as more quality rest. For those whose quality of sleep has improved, they have been spending more time in deep and REM sleep.

Take a look at the maps below to see how quality of sleep changed for different age groups in the US during the week that ended March 22, 2020.* The blue color represents an increase in minutes of average sleep, while the orange color represents a decrease. The numbers shown in

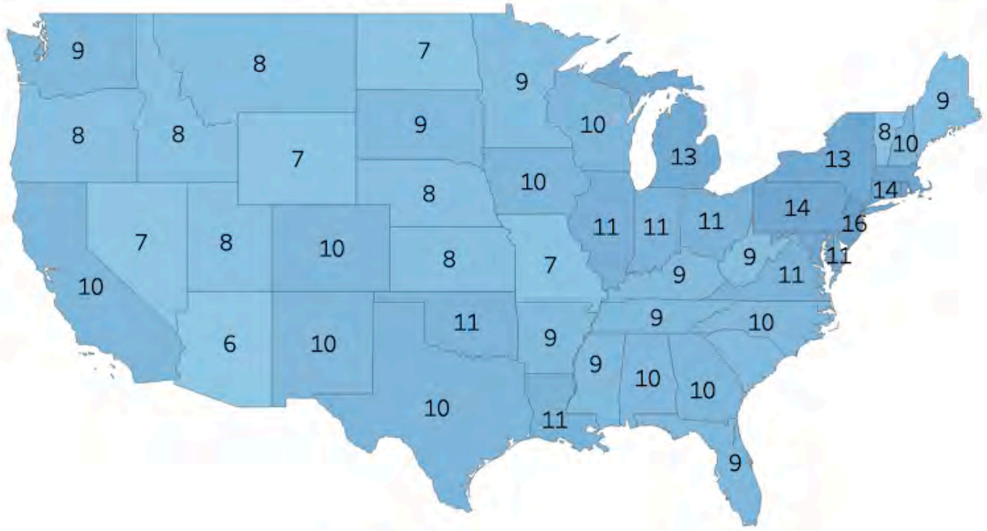
# Impact of COVID-19 on Sleep

Change in Sleep Minutes
Week Ending 3/22

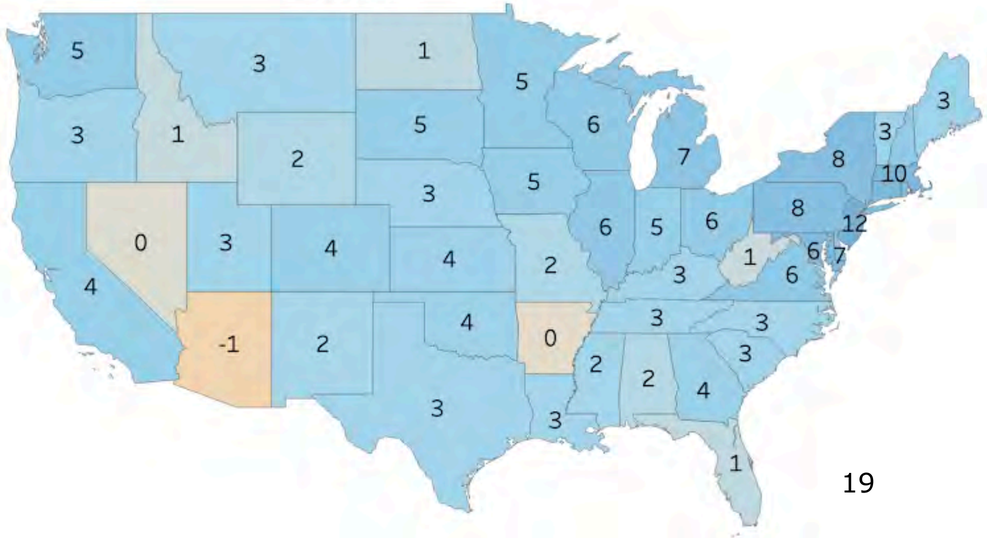
18-29



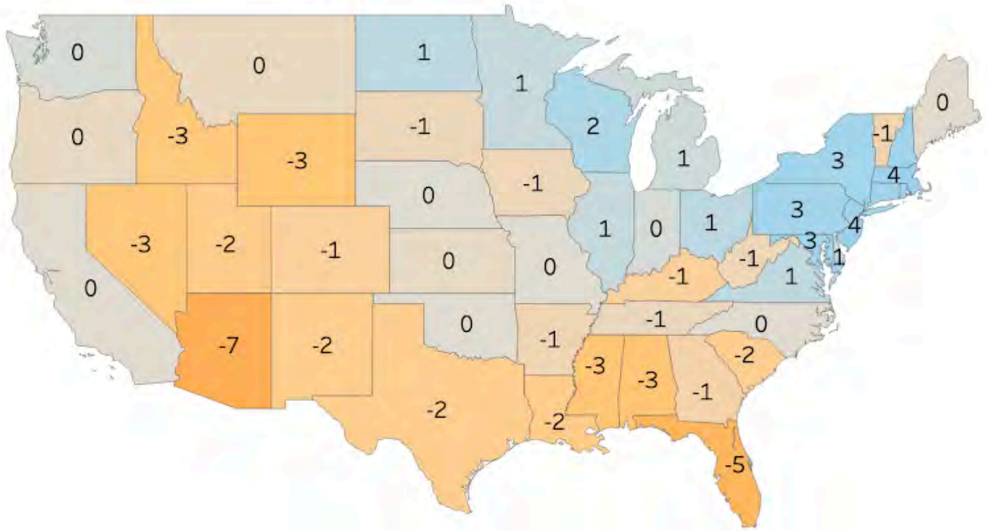

30-49



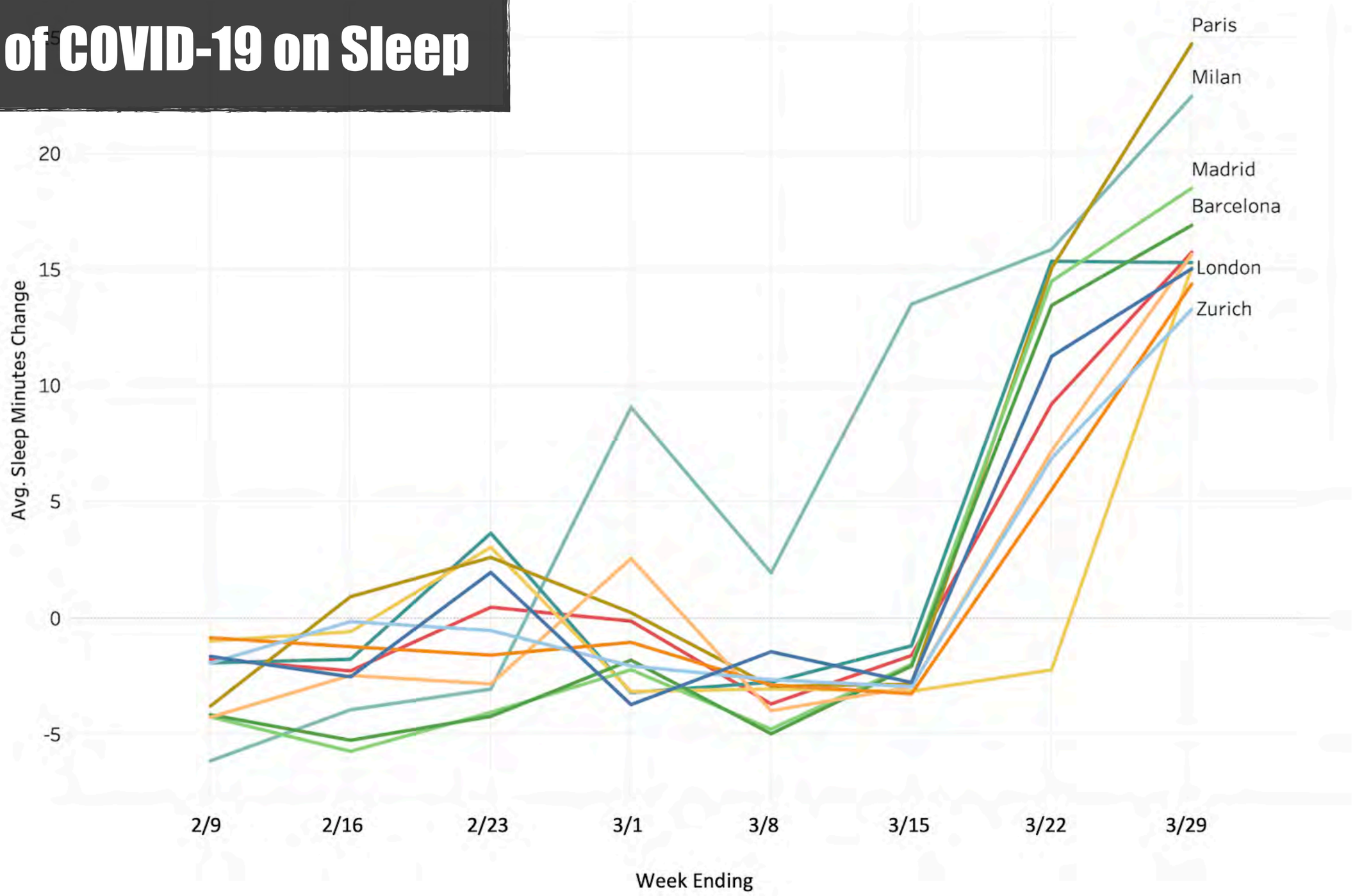

50-64




65+

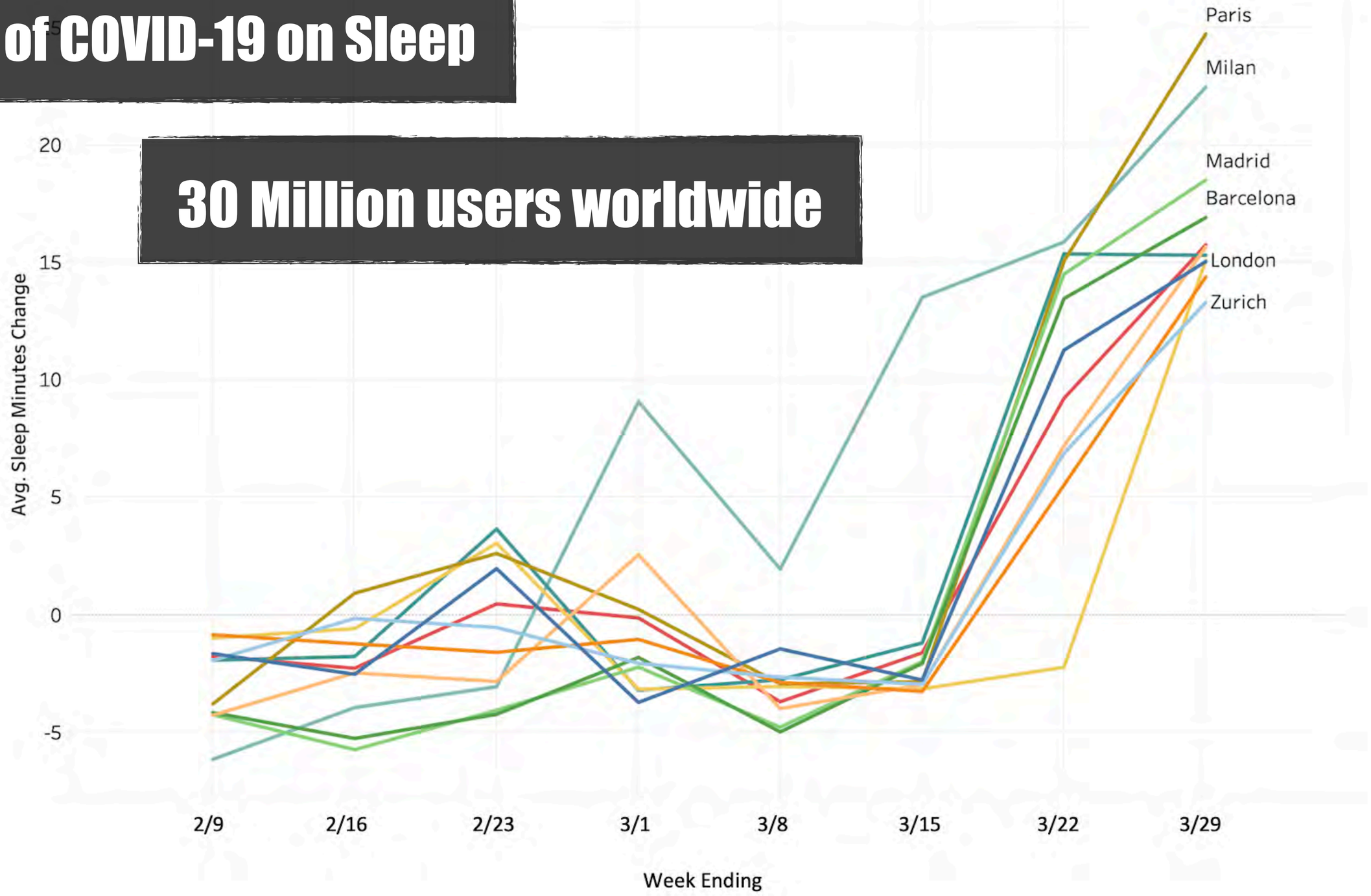


# Impact of COVID-19 on Sleep



# Impact of COVID-19 on Sleep

## 30 Million users worldwide



# IMPACT OF COVID-19 ON HEALTH BEHAVIOURS

# Smart Thermostat

ecobee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# Why ecobee Smart Thermostats?

- Over 1.4M ecobee smart thermostats in the market.
- 50.000 free ecobee thermostats distributed by the province of Ontario alone.
- Additional funding programs in BC, Alberta, and Quebec.
- 150.000+ unique datasets available through the ***Donate Your Data*** program (including mine).




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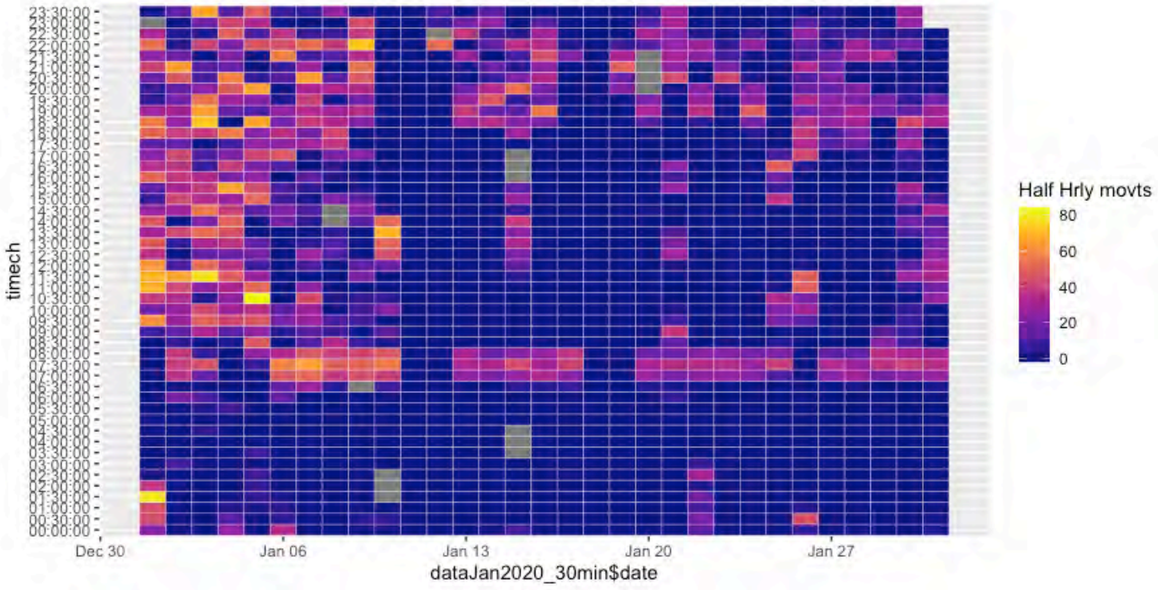
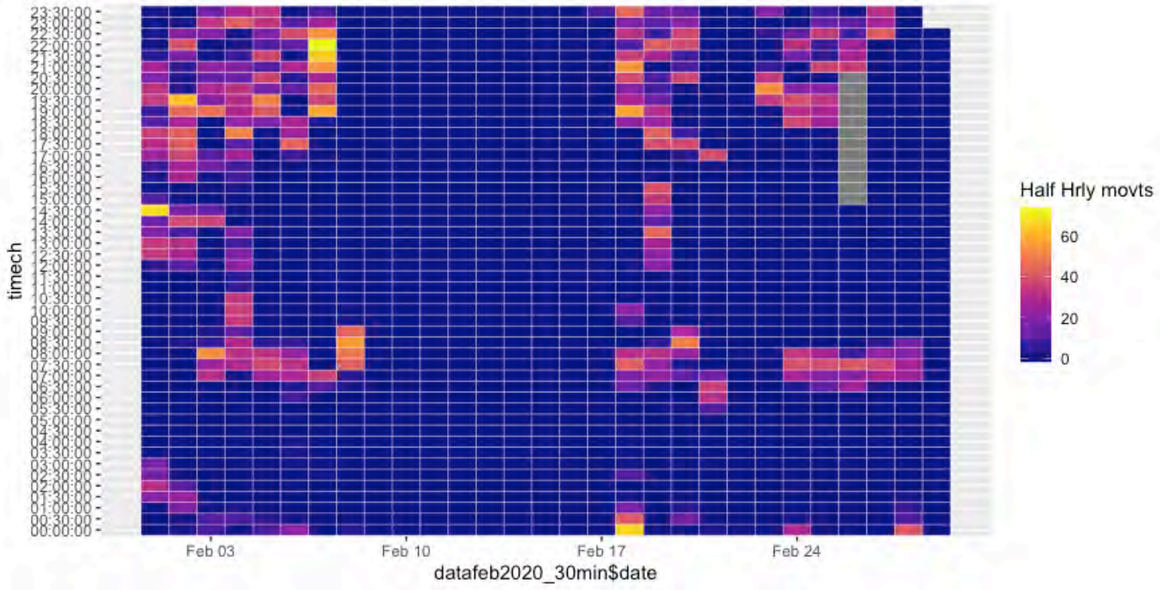
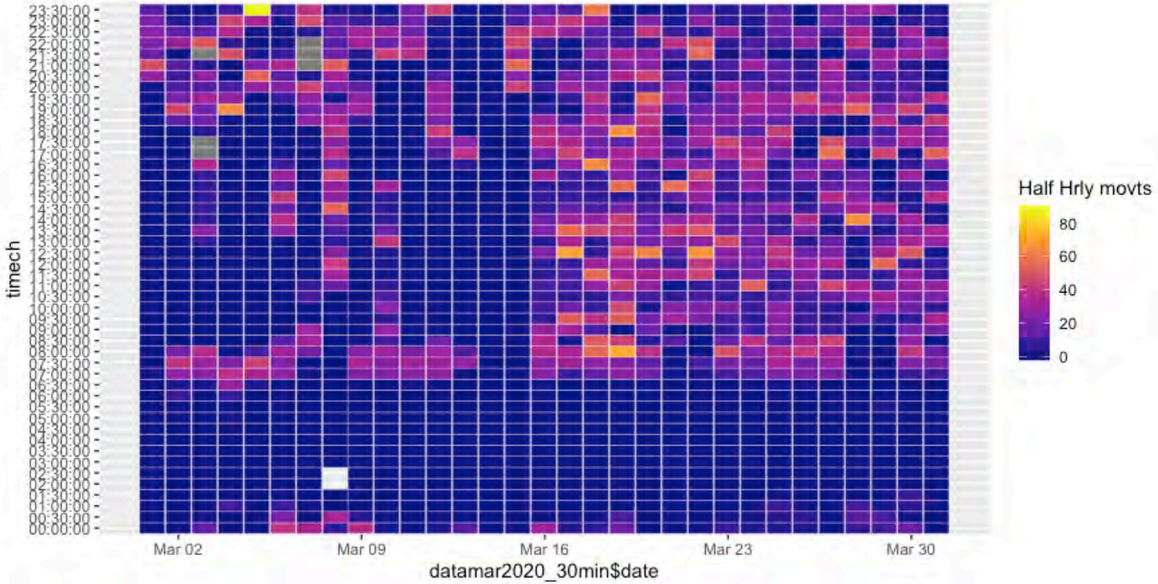
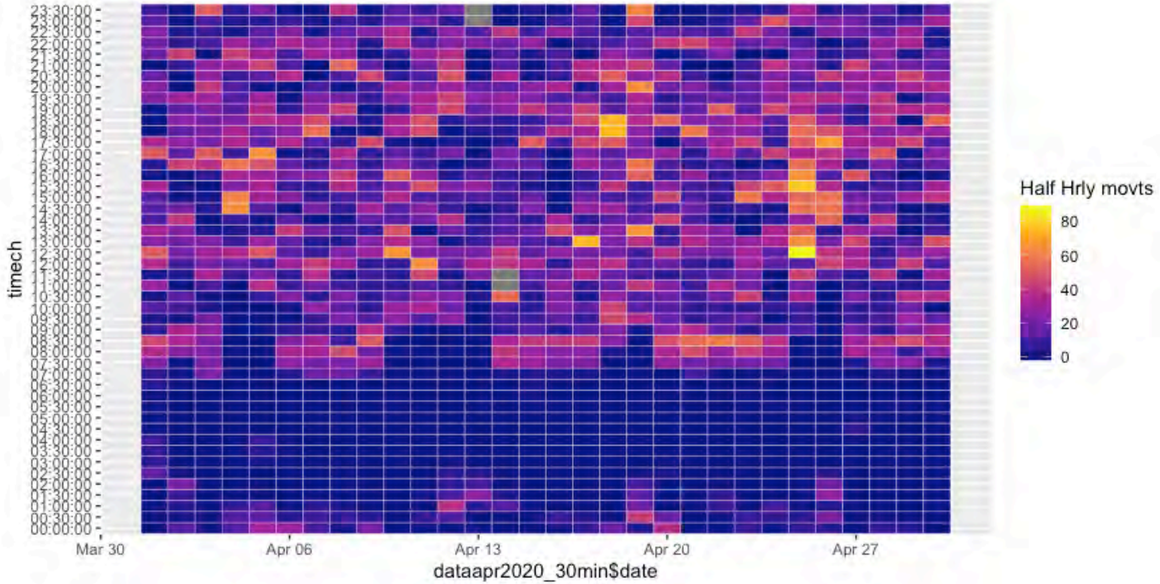
love
another

# Impact of COVID-19

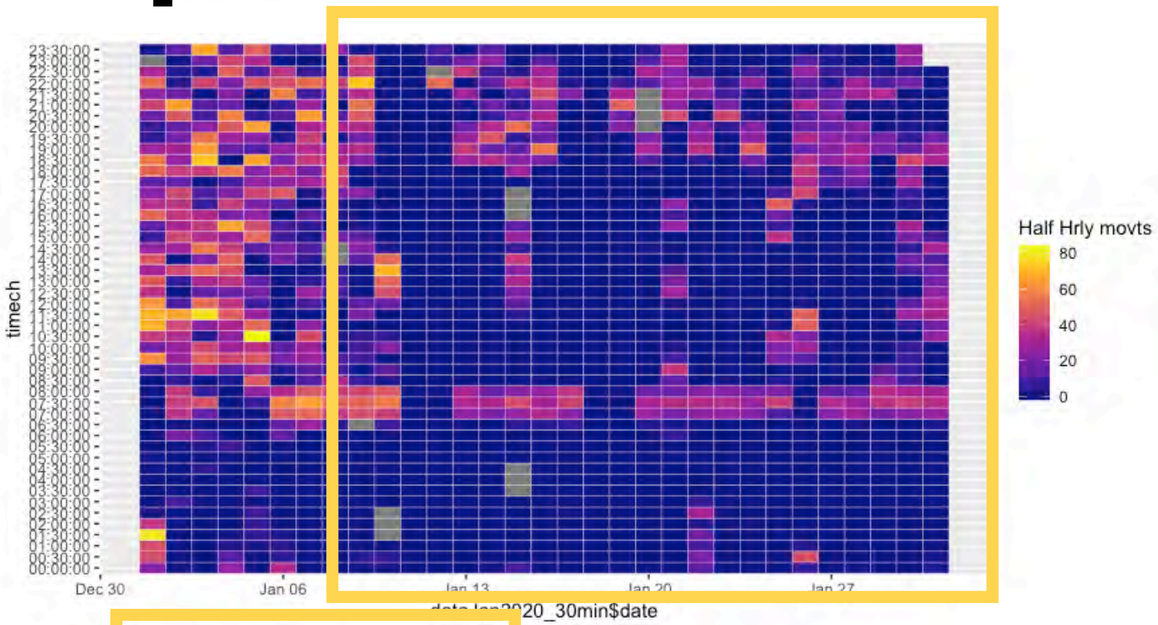


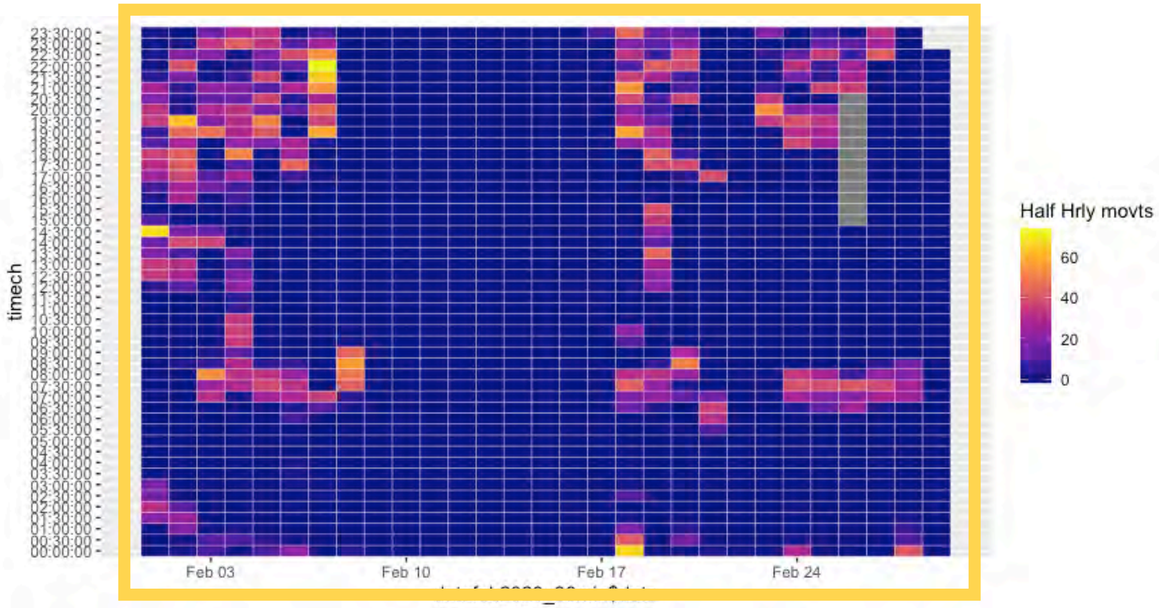



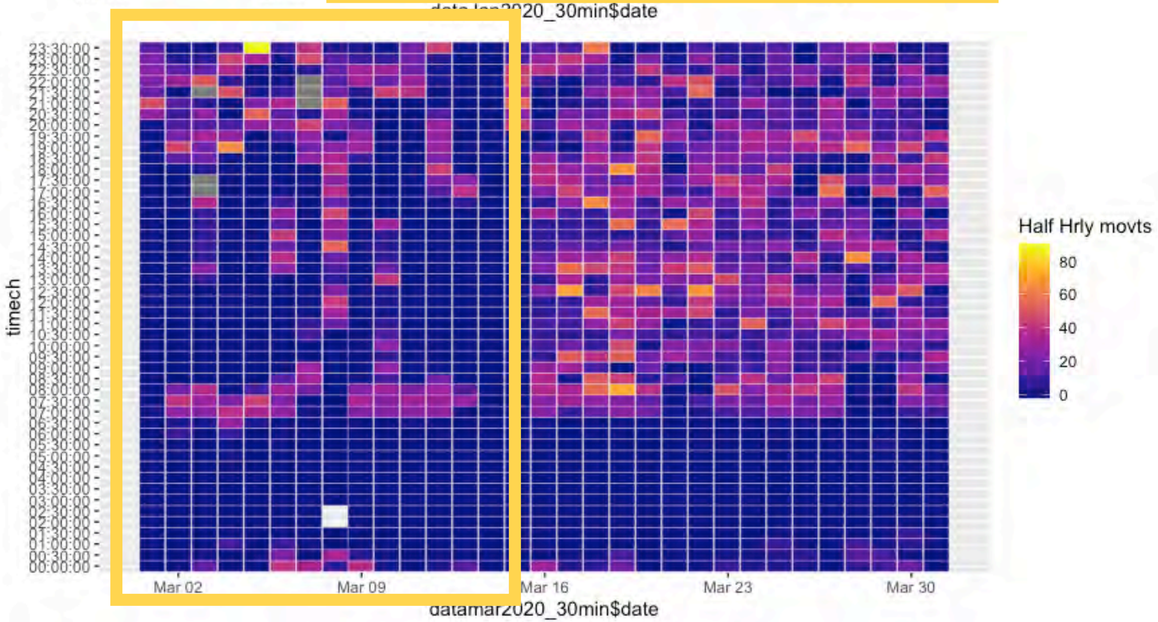



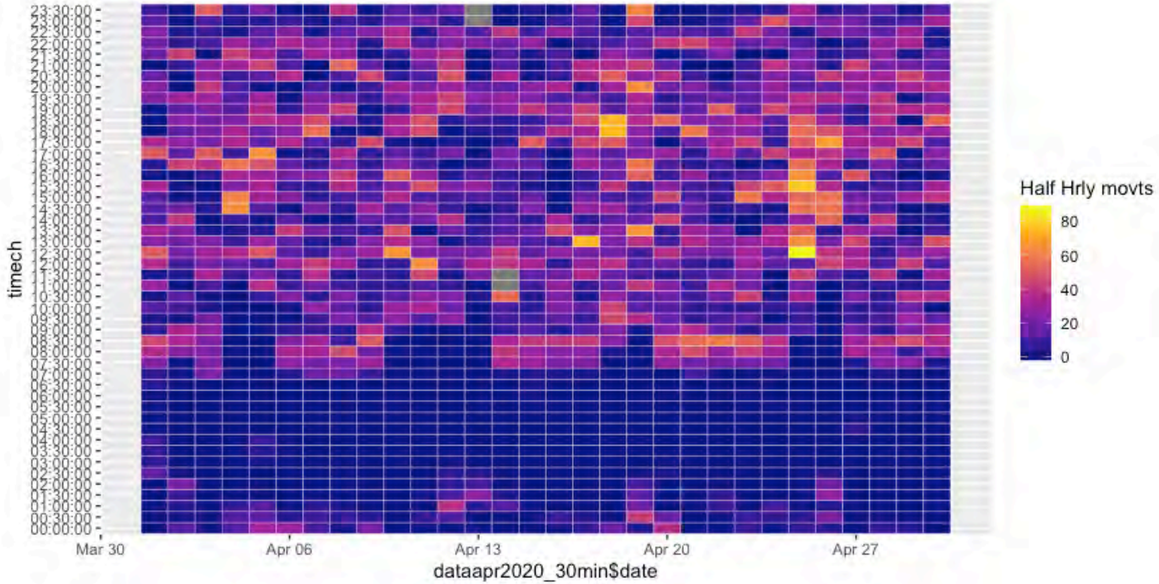



# Impact of COVID-19

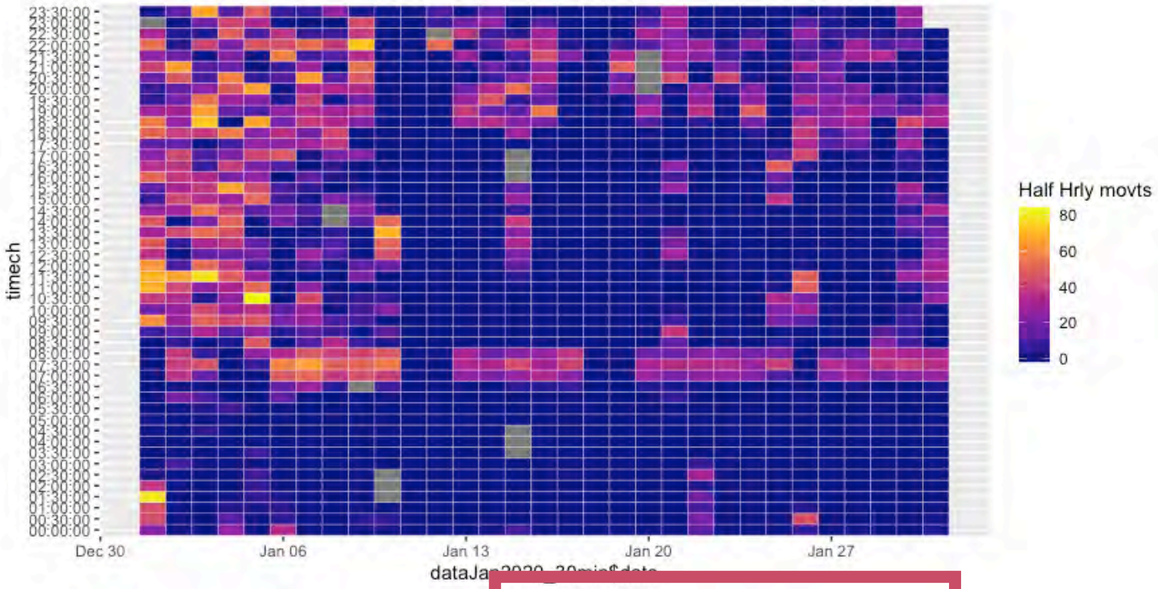


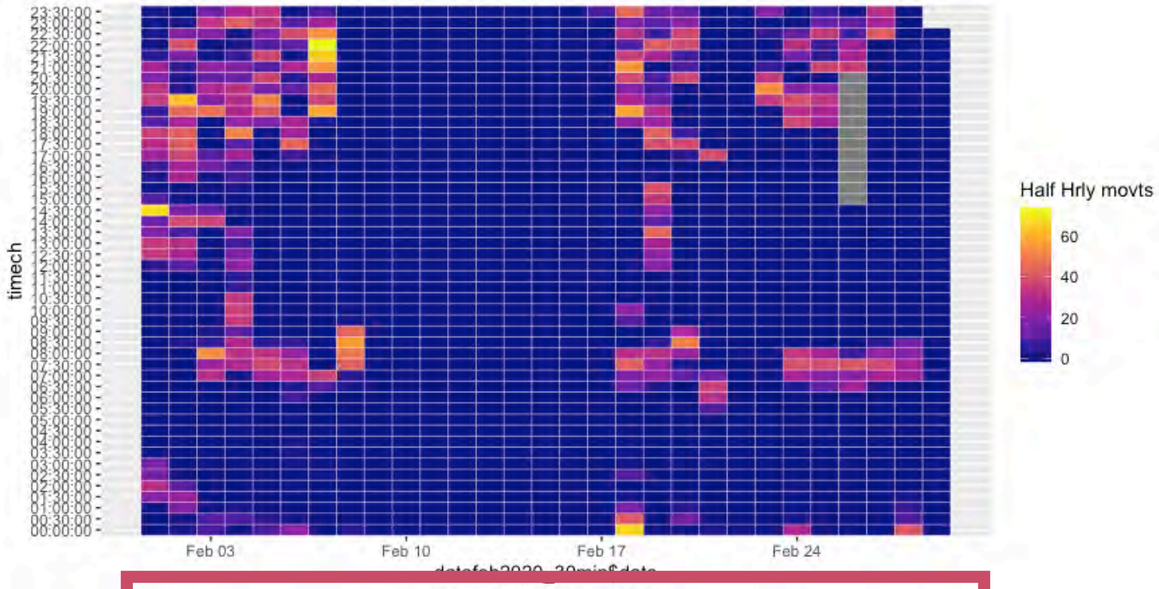



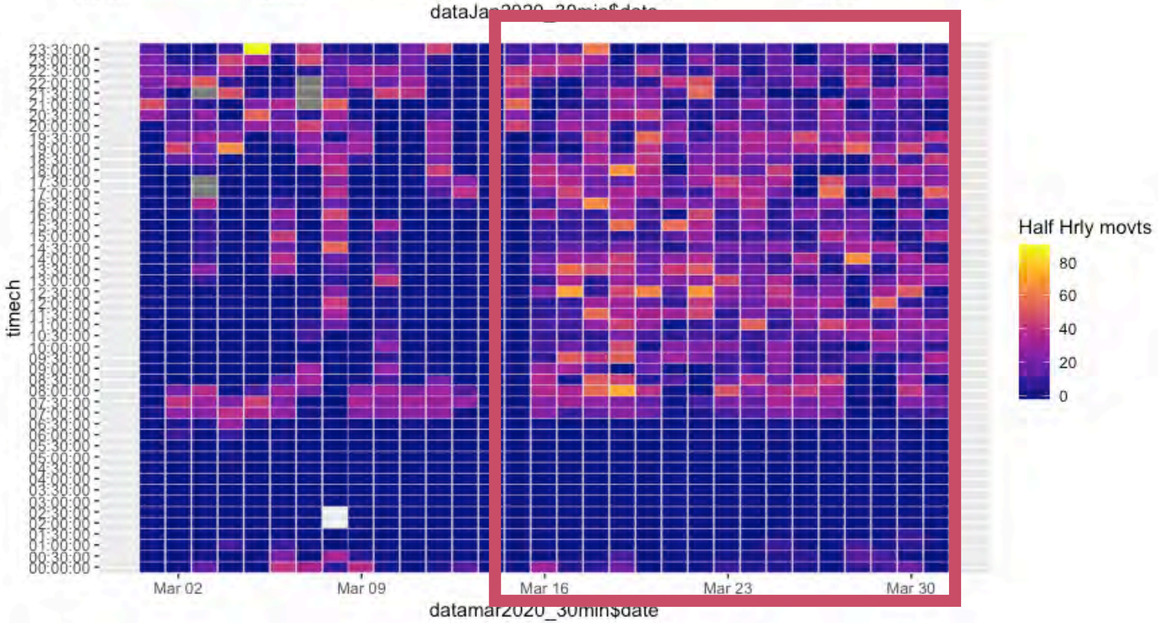



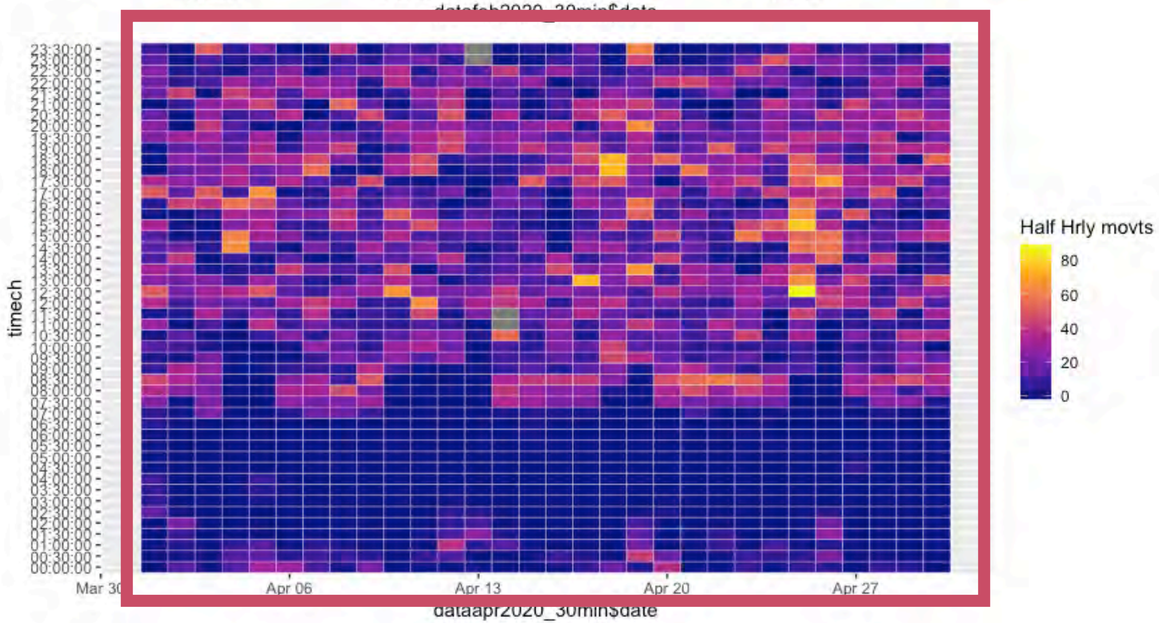



# Impact of COVID-19



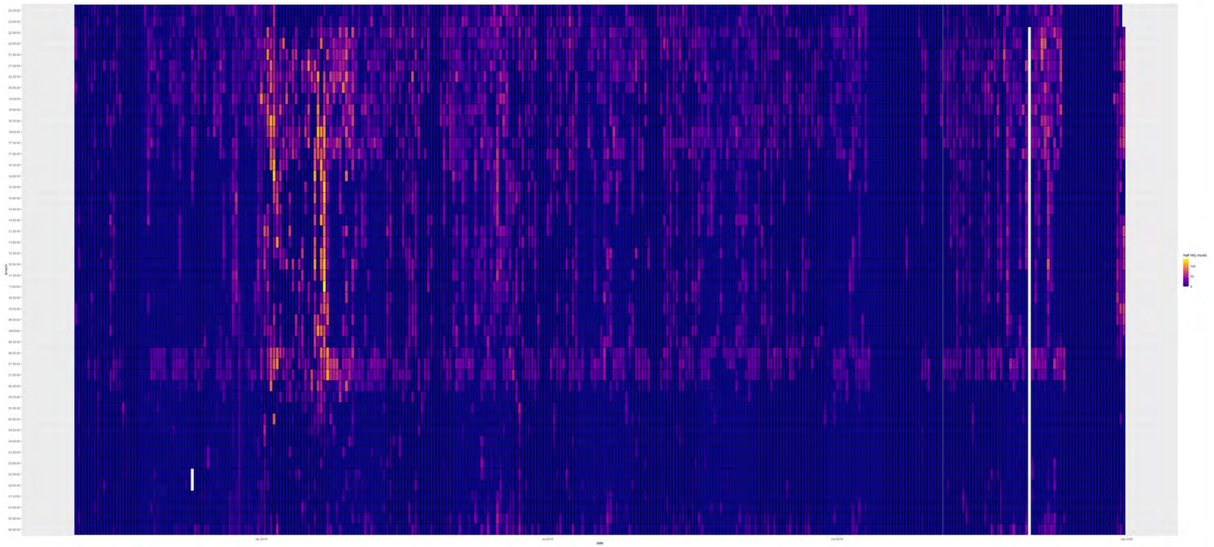



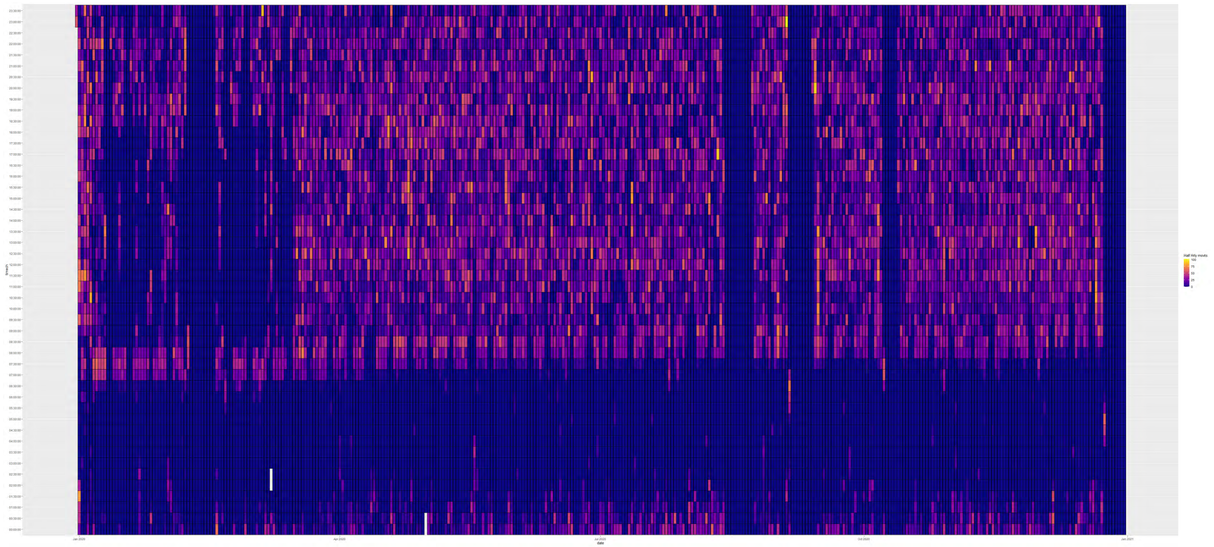



# Impact of COVID-19

2019



2020



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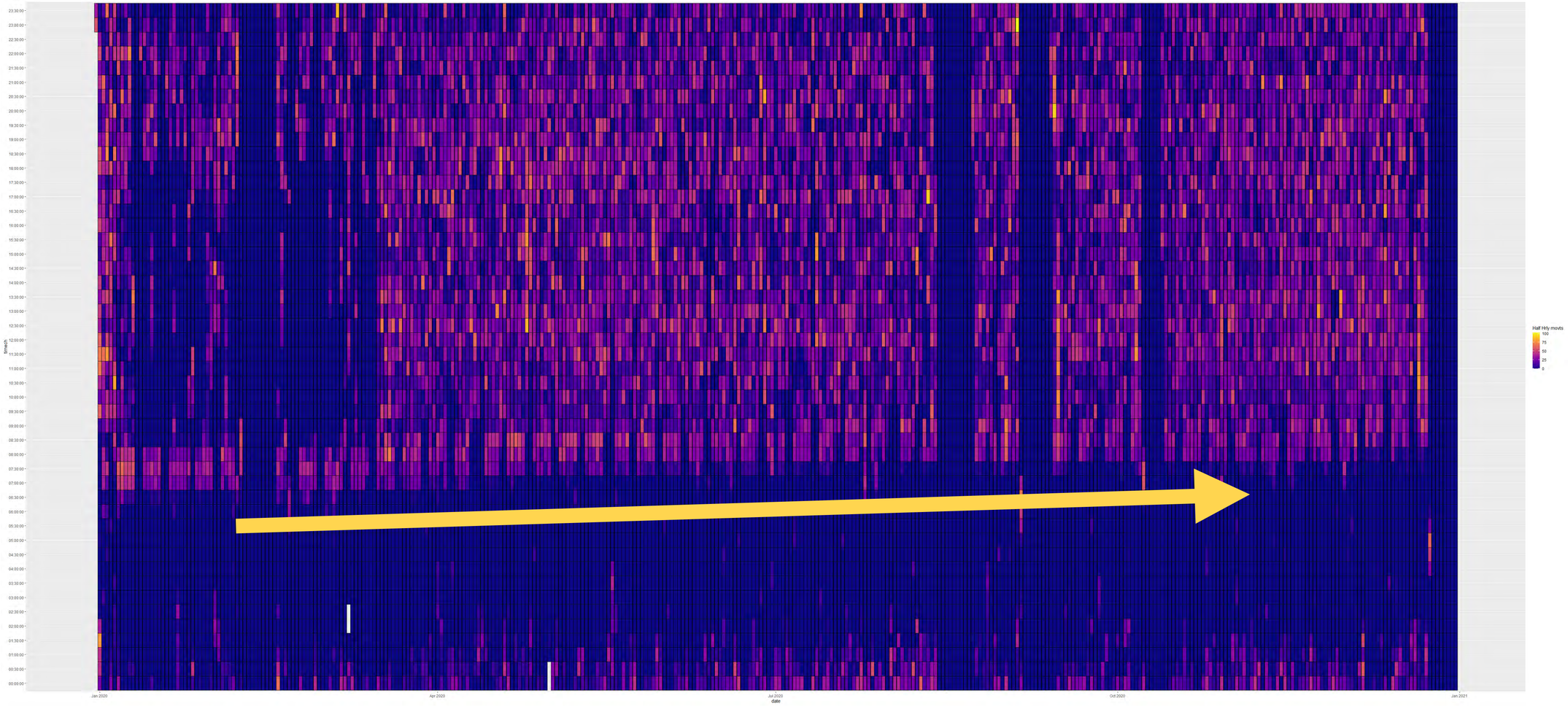
# Impact of COVID-19

Wake up time - 2020

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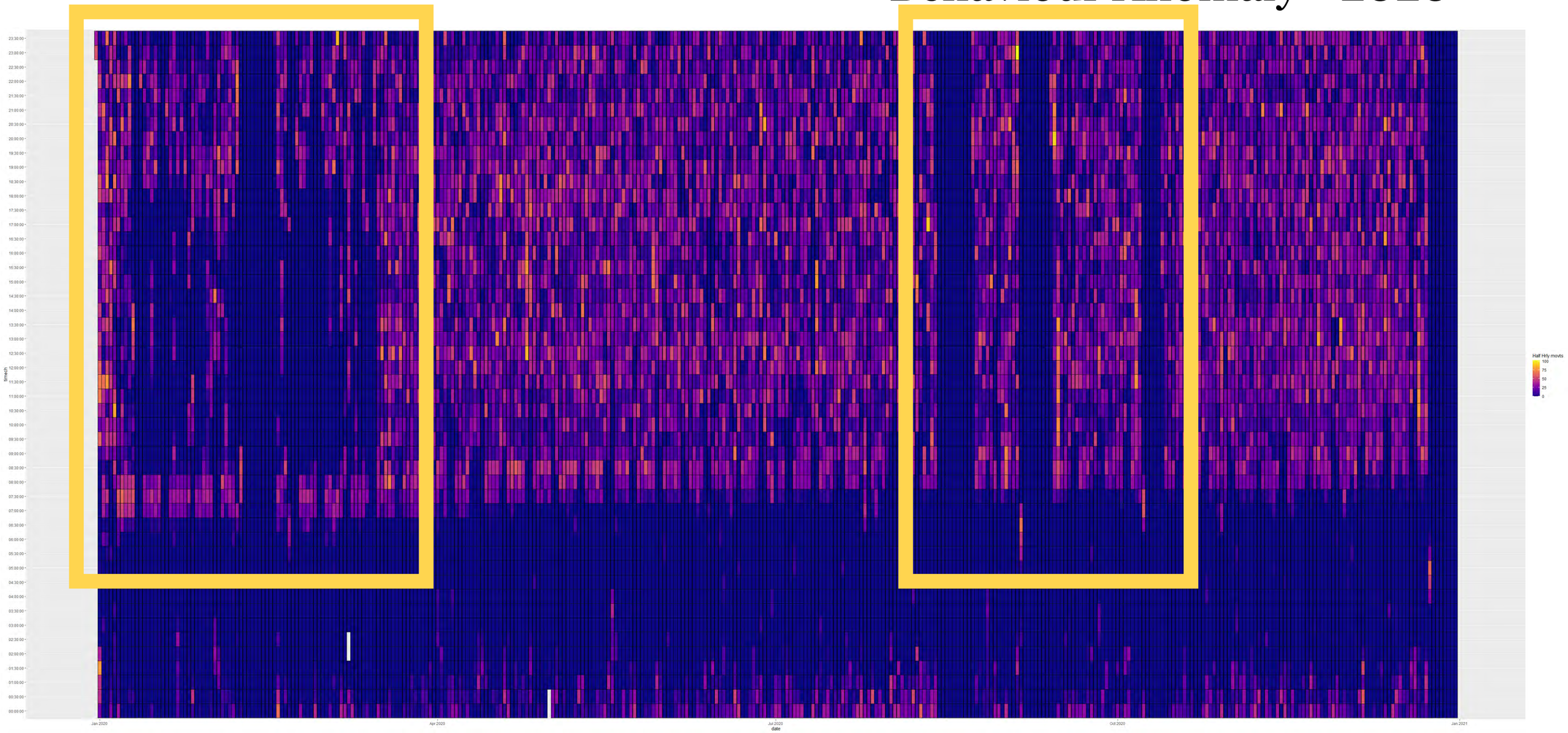
# Potential for Remote Monitoring

Behaviour Anomaly - 2020

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# GREATEST DATA CHALLENGES IN PUBLIC HEALTH RESEARCH AND PRACTICE

# Lack Consistent Data Structure an Data Repositories

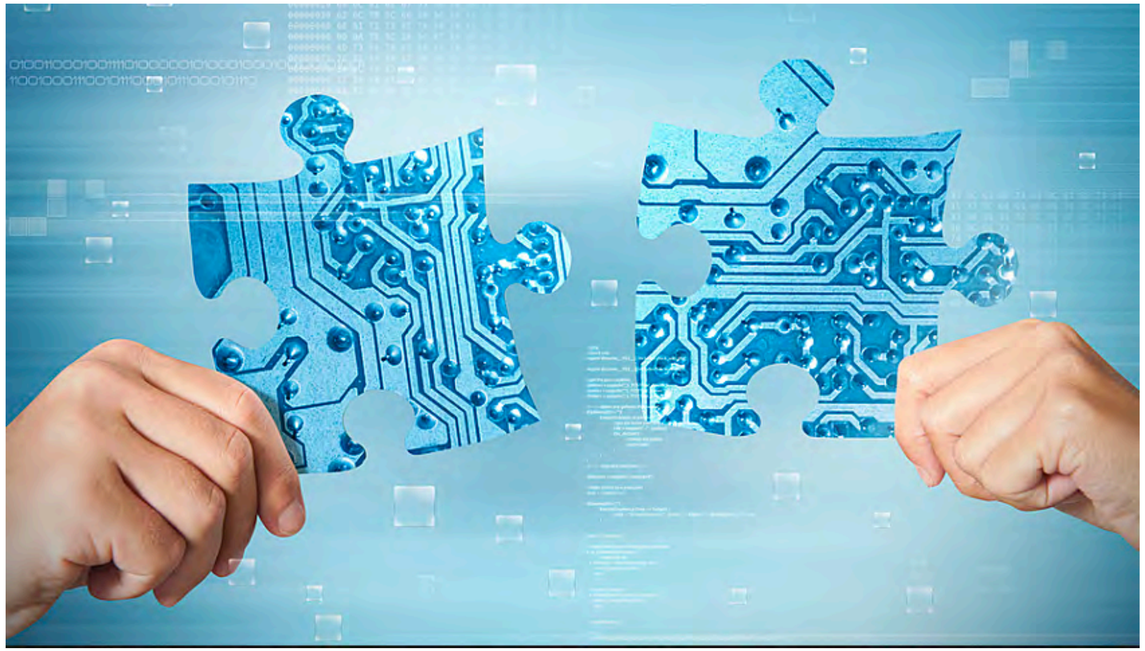
While data is widely collected through different systems and sensory technologies, accessing and integrating all these datasets can be really challenging.

***Challenges***

- Data collected is often stored using company-specific data models
- Data is often siloed and hidden behind corporate and institutional walls
- Companies and institutions do not have the necessary expertise to create secure and privacy-presenting data sharing programs.

***Consequences***

- Relevant data that could have a positive effect on public health practices is often unused.



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# Lack Consistent Data Structure an Data Repositories

frontiers in Public Health

PERSPECTIVE
published: 17 February 2016
doi: 10.3389/fpubh.2016.00007

## Who Owns the Data? Open Data for Healthcare

*Patty Kostkova[1]*, Helen Brewer[2], Simon de Lusignan[3], Edward Fottrell[4], Ben Goldacre[5], Graham Hart[4], Phil Koczan[6], Peter Knight[7], Corinne Marsolier[8], Rachel A. McKendry[9], Emma Ross[10], Angela Sasse[1], Ralph Sullivan[11], Sarah Chaytor[12], Olivia Stevenson[12], Raquel Velho[13] and John Tooke[14]*

*[1] Department of Computer Science, University College London (UCL), London, UK, [2] Parliamentary Office of Science and Technology, London, UK, [3] Department of Clinical and Experimental Medicine, University of Surrey, Guildford, and Royal College of General Practitioners Research and Surveillance Centre, London, UK, [4] Faculty of Population Health Sciences, University College London (UCL), London, UK, [5] London School of Hygiene & Tropical Medicine, London, UK, [6] University College London Partners (UCLP), London, UK, [7] Department of Health, London, UK, [8] Cisco Consulting Services, Life Sciences, Health and Care, Paris, France, [9] The London Centre for Nanotechnology and Division of Medicine, University College London (UCL), London, UK, [10] Chatham House Centre on Global Health Security, London, UK, [11] Health Informatics Group, Royal College of General Practitioners, London, UK, [12] UCL Public Policy, UCL, London, UK, [13] Department of Science and Technology Studies, UCL, London, UK, [14] School of Life and Medical Sciences, UCL, London, UK*

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*Andreas Holzinger,*
*Medical University of Graz, Austria*
*Pier Luigi Lopalco,*

Research on large shared medical datasets and data-driven research are gaining fast momentum and provide major opportunities for improving health systems as well as individual care. Such open data can shed light on the causes of disease and effects of treatment, including adverse reactions side-effects of treatments, while also facilitating analyses tailored to an individual's characteristics, known as personalized or "stratified medicine." Developments, such as crowdsourcing, participatory surveillance, and individuals pledging to become "data donors" and the "quantified self" movement (where cit-

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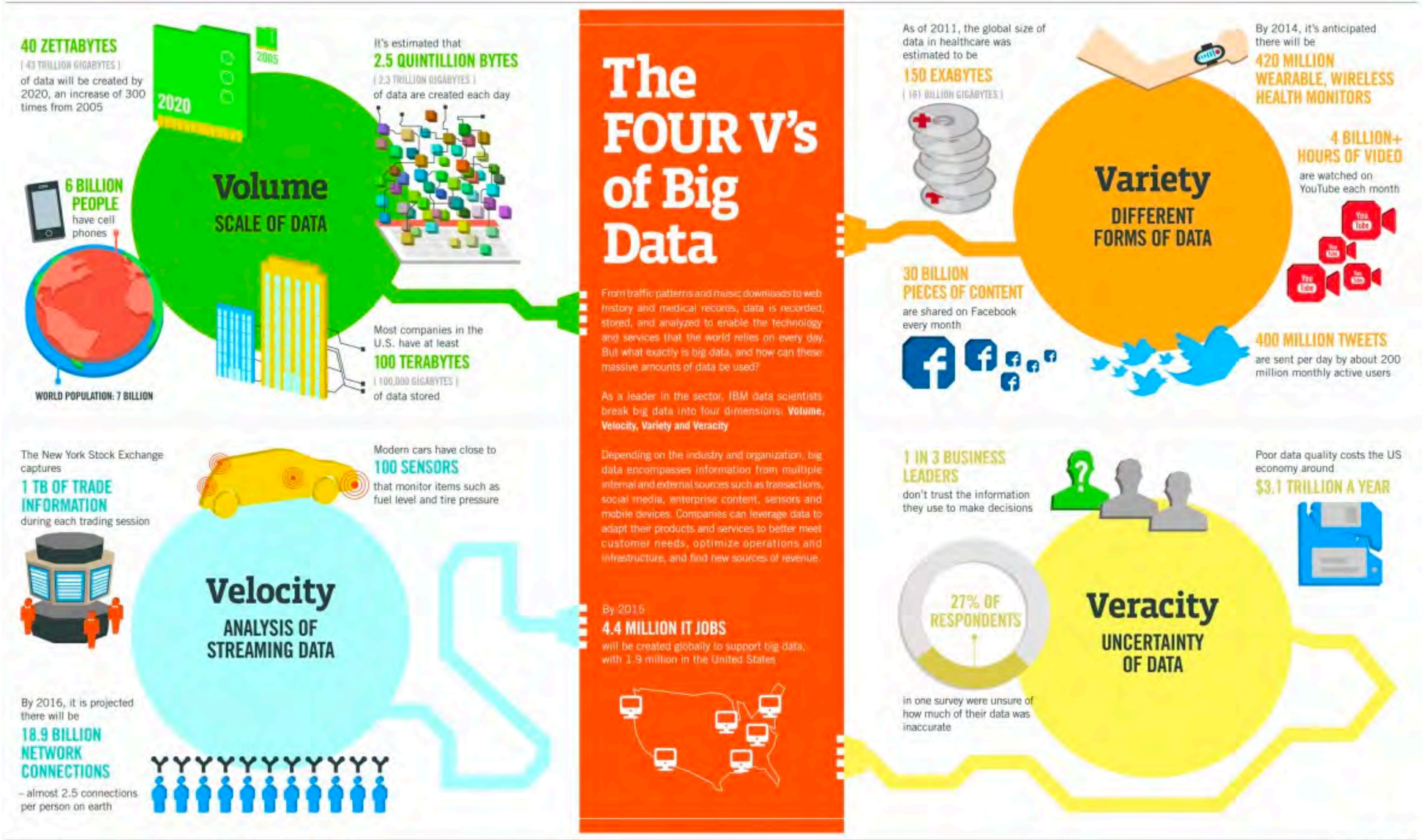
# Big Data

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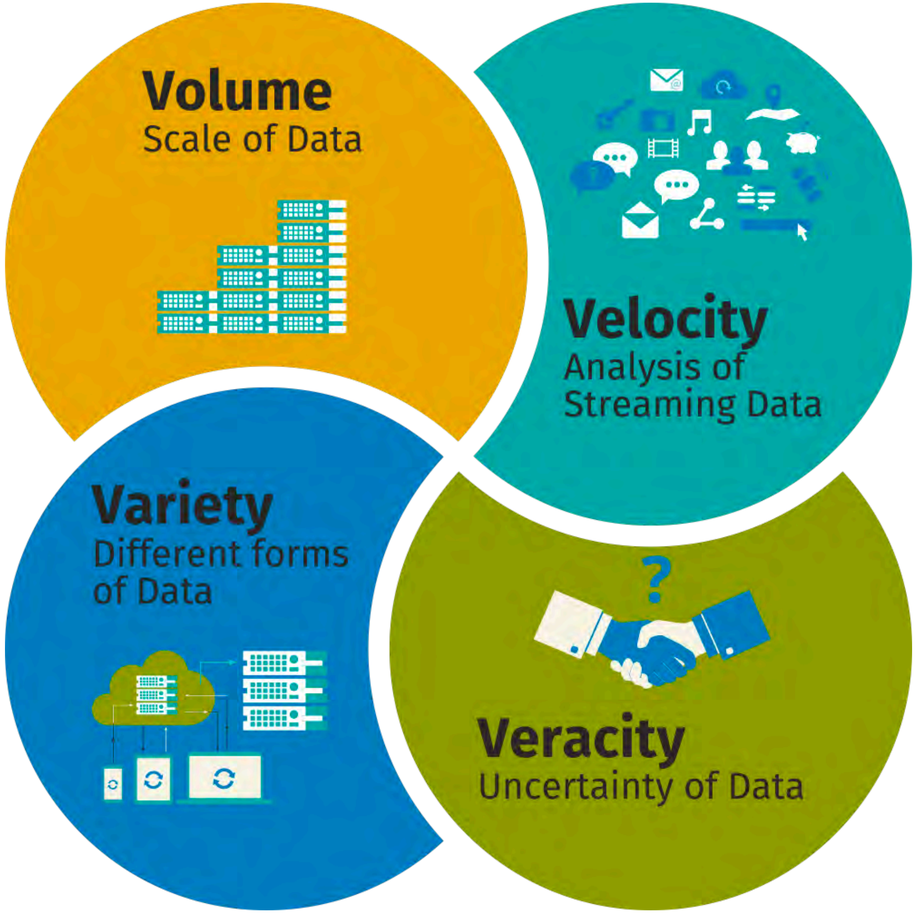
# Big Data

Remember the four Vs, as they will define many of the challenges that we will be discussing in this lecture.




### *Challenges*

- Public health officials are not equipped to work with real-time data.
- Large volumes of useful data are being collected, but our public health practice is not trained to use this data.

### *Consequences*

- Decisions in Public Health are often informed by outdated data
- Time and effort needs to be placed on creating tools and repositories that public health officials can use.

# Big Data

Prosperi *et al. BMC Medical Informatics and Decision Making* (2018) 18:139
https://doi.org/10.1186/s12911-018-0719-2

BMC Medical Informatics and Decision Making

DEBATE Open Access

## Big data hurdles in precision medicine and precision public health

Mattia Prosperi[1*], Jae S. Min[1], Jiang Bian[2] and François Modave[3]

**Abstract**

**Background:** Nowadays, trendy research in biomedical sciences juxtaposes the term 'precision' to medicine and public health with companion words like big data, data science, and deep learning. Technological advancements permit the collection and merging of large heterogeneous datasets from different sources, from genome sequences to social media posts or from electronic health records to wearables. Additionally, complex algorithms supported by high-performance computing allow one to transform these large datasets into knowledge. Despite such progress, many barriers still exist against achieving precision medicine and precision public health interventions for the benefit of the individual and the population.

**Main body:** The present work focuses on analyzing both the technical and societal hurdles related to the development of prediction models of health risks, diagnoses and outcomes from integrated biomedical databases. Methodological challenges that need to be addressed include improving semantics of study designs: medical record data are inherently biased, and even the most advanced deep learning's denoising autoencoders cannot overcome the bias if not handled a priori by design. Societal challenges to face include evaluation of ethically actionable risk factors at the individual and population level; for instance, usage of gender, race, or ethnicity as risk modifiers, not as biological variables, could be replaced by modifiable environmental proxies such as lifestyle and dietary habits, household income, or access to educational resources.

**Conclusions:** Data science for precision medicine and public health warrants an informatics-oriented formalization of

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# How to Address These Issues

***Solutions***

- Government + Industry + Academia Partnerships to establish trusted repositories.
- Combine the following (TRUST Principles (Lin et al., 2020):
  - **T**ransparency (academia + government)
  - **R**esponsibility (academia + government)
  - **U**ser Focus (academia + industry)
  - **S**ustainability (government + industry)
  - **T**echnology (academia + industry)

***Example:***

- Canadian Personalized Health Information Network (https://www.cphin.ca/

CPHIN

**This federally incorporated not-for-profit entity aims to make health data findable and accessible, ultimately helping patients tailor their own health decisions in partnership with physicians.**

Lin, D., Crabtree, J., Dillo, I., Downs, R. R., Edmunds, R., Giaretta, D., ... & Khodiyar, V. (2020). The TRUST Principles for digital repositories. Scientific Data, 7(1), 1-5.

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# How to Address These Issues

www.nature.com/scientificdata

SCIENTIFIC DATA

Check for updates

OPEN

COMMENT

## The TRUST Principles for digital repositories

Dawei Lin[1]✉, Jonathan Crabtree[2], Ingrid Dillo[3], Robert R. Downs[4], Rorie Edmunds[5], David Giaretta[6], Marisa De Giusti[7], Hervé L'Hours[8], Wim Hugo[9], Reyna Jenkyns[10], Varsha Khodiyar[11], Maryann E. Martone[12], Mustapha Mokrane[3], Vivek Navale[13], Jonathan Petters[14], Barbara Sierman[15], Dina V. Sokolova[16], Martina Stockhause[17] & John Westbrook[18]

**As information and communication technology has become pervasive in our society, we are increasingly dependent on both digital data and repositories that provide access to and enable the use of such resources. Repositories must earn the trust of the communities they intend to serve and demonstrate that they are reliable and capable of appropriately managing the data they hold.**

Following a year-long public discussion and building on existing community consensus[1], several stakeholders, representing various segments of the digital repository community, have collaboratively developed and endorsed a set of guiding principles to demonstrate digital repository trustworthiness. Transparency, Responsibility, User focus, Sustainability and Technology: the TRUST Principles provide a common framework to facilitate discussion and implementation of best practice in digital preservation by all stakeholders.

### Context and History

For over sixty years, digital data stewardship and preservation have been central to the mission of academic institutions such as libraries, archives, and domain repositories[2] with many other stakeholders involved, including researchers, funders, infrastructure, and service providers. Scientific data management is receiving increasing

Lin, D., Crabtree, J., Dillo, I., Downs, R. R., Edmunds, R., Giaretta, D., ... & Khodiyar, V. (2020). The TRUST Principles for digital repositories. Scientific Data, 7(1), 1-5.

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# CLOUD COMPUTING

# Cloud Computing

***Benefits***

- *Scalability*
- *Easy development of multi-stakeholder systems*
- *Remote access and infrastructure to support access control*
- *Pay as you go models*

***Risks***

- *Shared hardware - Backup challenges*
- *Less control over what is happening with your data*
- *Leaks and unforeseen attacks*
- https://www.hhs.gov/hipaa/for-professionals/special-topics/health-information-technology/cloud-computing/index.html

***Examples***

- *MS Azure (https://azure.microsoft.com/en-ca/)*
- *Amazon AHS (https://aws.amazon.com/)*

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# Cloud Computing

frontiers in Public Health

REVIEW
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## Big Data's Role in Precision Public Health

*Shawn Dolley**

*Cloudera, Inc., Palo Alto, CA, United States*

Precision public health is an emerging practice to more granularly predict and understand public health risks and customize treatments for more specific and homogeneous subpopulations, often using new data, technologies, and methods. Big data is one element that has consistently helped to achieve these goals, through its ability to deliver to practitioners a volume and variety of structured or unstructured data not previously possible. Big data has enabled more widespread and specific research and trials of stratifying and segmenting populations at risk for a variety of health problems. Examples of success using big data are surveyed in surveillance and signal detection, predicting future risk, targeted interventions, and understanding disease. Using novel big data or big data approaches has risks that remain to be resolved. The continued growth in volume and variety of available data, decreased costs of data capture, and emerging computational methods mean big data success will likely be a required pillar of precision public health into the future. This review article aims to identify the precision public health use cases where big data has added value, identify classes of value that big data may bring, and outline the risks inherent in using big data in precision public health efforts.

OPEN ACCESS

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# CONSENT AND DATA REGULATIONS

# Informed Consent

- According to the FDA, the main deficiencies related to consent management are:
  - Failure to obtain consent or re-consent;
  - Use of expired, incomplete or non-validated forms;
  - Failure to provide copies of the forms to study subjects or missing documents;
  - Changes made to forms by hand and without approval of Review Ethic Boards.

- In addition, consent is not always a static process, and re-consent must be sought in several cases.

# INFORMED CONSENT AND ACTIVE ASSISTED LIVING

# Informed Consent and Active Assisted Living (AAL)

- Active Assisted Living (AAL) technologies refer to "technologies that are designed to improve quality of life, bring independence, and enable healthier lifestyles for those who need assistance”

- AAL and smart technologies increase the complexity of data collection points and, in turn, of consent management.

- This makes it harder to know **when, why** and **where** data is being collected.

Fadrique, Laura Xavier, Dia Rahman, and Plinio Pelegrini Morita. 2018. “The Active Assisted Living Landscape in Canada.”



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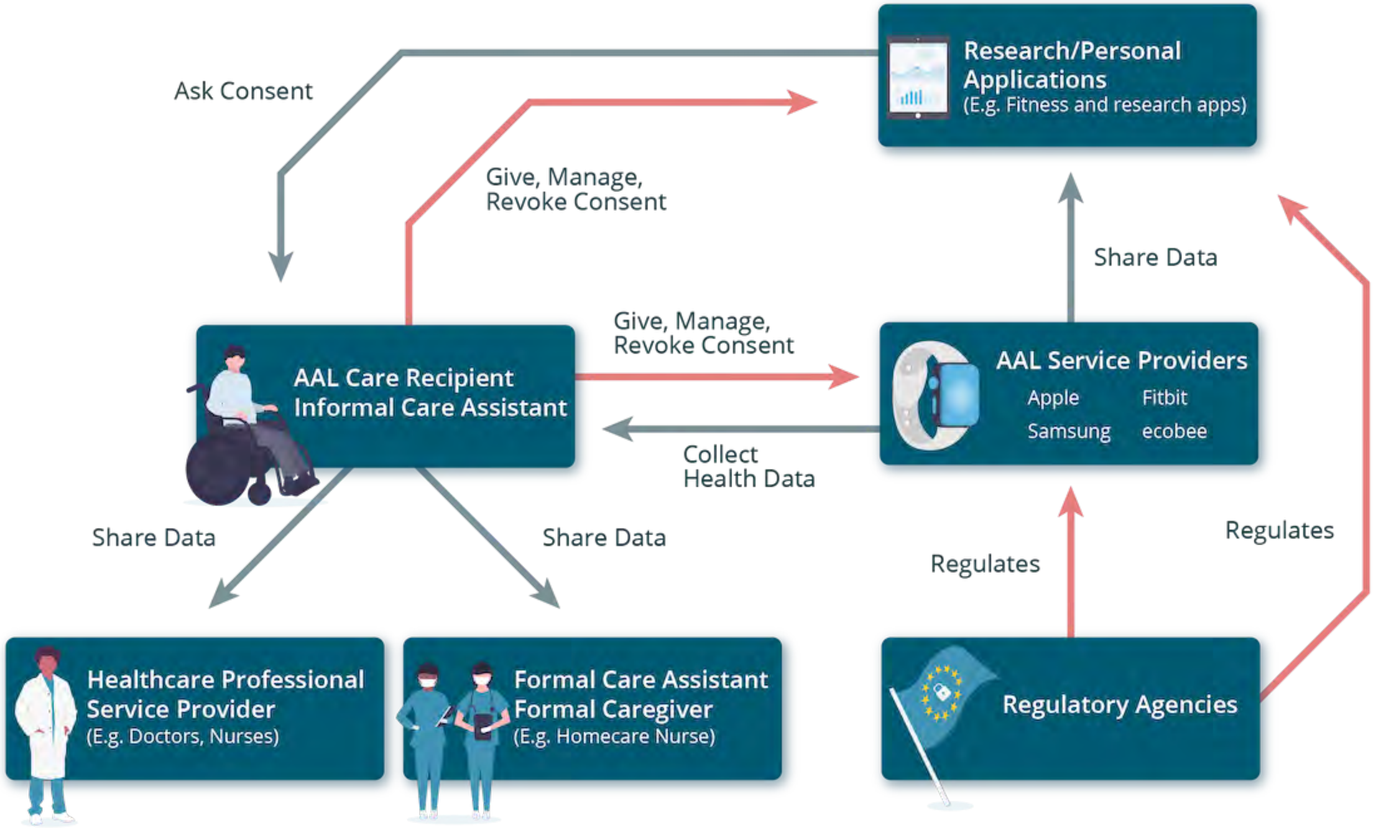
# Informed Consent and Active Assisted Living (AAL)

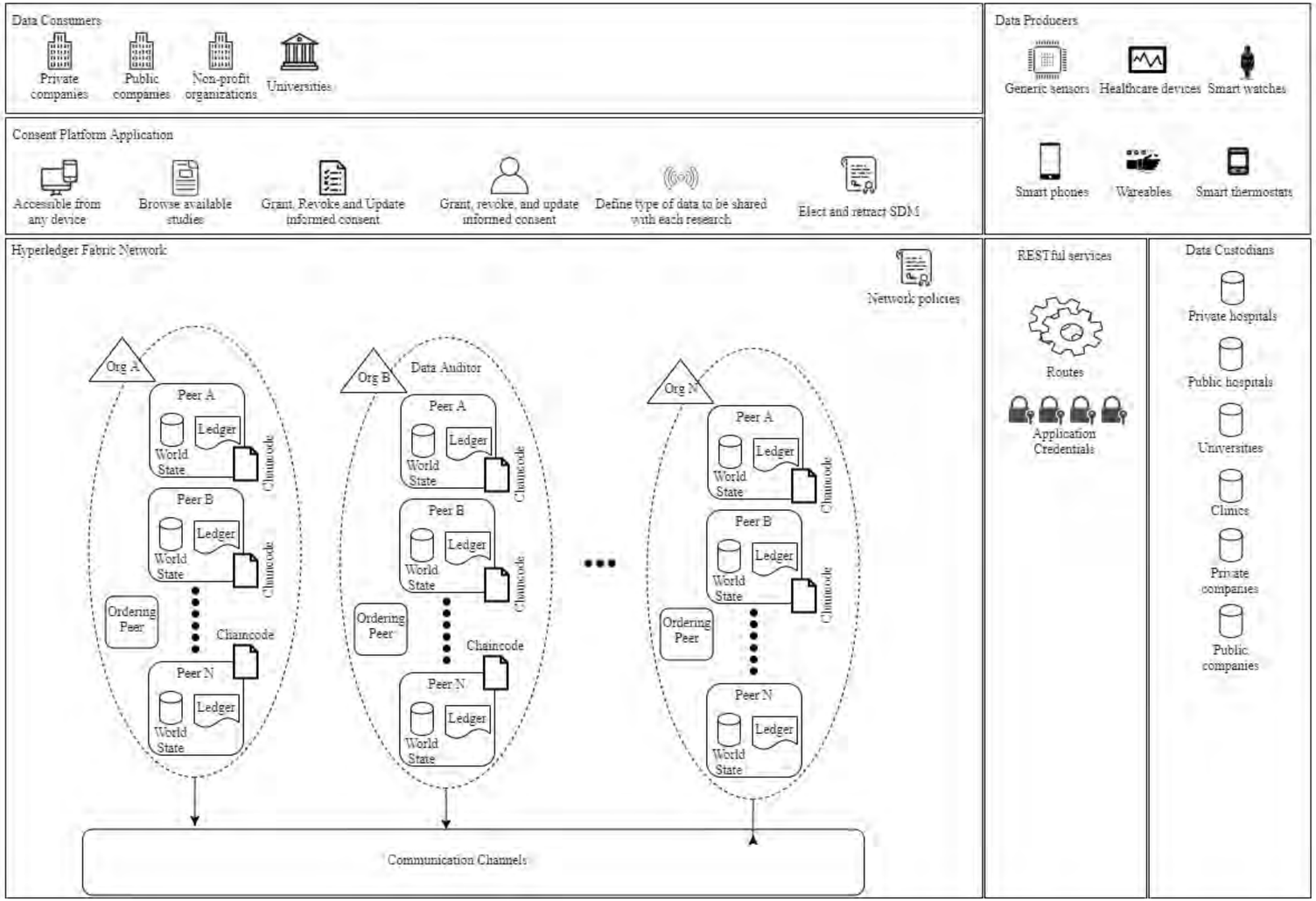


# Blockchain

- Blockchain is a tamperproof digital ledger where all participants view one, immutable version of the truth.
  - Decentralized and Distributed: No central controlling authority / No single point of failure
  - Immutable and timestamped log of events for network participants: Transparency / Compliance
  - Increase Trust Among Parties

- Therefore, a Blockchain platform can provide an immutable and timestamped log of consent, increasing transparency and minimizing trust issues.

# Solution Blockchain Architecture

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# GDPR

# GDPR

The General Data Protection Regulation — or the GDPR - regulates and protects the processing of personal information. It outlines new data protection laws and principles that expand the privacy rights, granted to individuals. The GDPR ensures companies to be transparent about the personal data they handle and have a legitimate purpose for using it.

The GDPR provides expanded rights for individuals. Customers have the right to:

- Obtain confirmation as to whether or not their personal data is being processed, where and for what purpose (Right to Access)
- Access their personal data (Right to Access)
- Correct errors in their personal data (Right to Access)
- Erase their personal data (Right to be Forgotten)
- Object to having their personal data processed (Right to be Forgotten)
- Receive a copy of any personal data stored, and transfer that data to another vendor/controller (Data Portability)


https://composity.com/blog/eu-general-data-protection-regulation-in-nutshell#:~:text=In%20a%20nutshell%2C%20the%20GDPR,It's%20a%20breakthrough%20directive.

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# Privacy

ANNUAL REVIEWS

*Annual Review of Public Health*

## Big Data in Public Health: Terminology, Machine Learning, and Privacy

Stephen J. Mooney[1] and Vikas Pejaver[2]

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**Keywords**

public health, big data, machine learning, privacy, training

**Abstract**

The digital world is generating data at a staggering and still increasing rate. While these "big data" have unlocked novel opportunities to understand public health, they hold still greater potential for research and practice. This review explores several key issues that have arisen around big data. First, we

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# Thank you!

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