The Ubiquitous Health Technology Lab

Advancing the Role of IoT in Public Health Research

Plinio P. Morita
Associate Professor
School of Public Health and Health Systems, University of Waterloo
Plinio Pelegrini Morita, PhD MSc PEng

**Associate Professor**
Former J.W. Graham Information Technology Emerging Leader Chair in Applied Health Informatics (2016-2021)
Director of the Ubiquitous Health Technology Lab
Research Scientist at the Research Institute for Aging
School of Public Health and Health Systems
University of Waterloo

**Assistant Professor**
Institute of Health Policy, Management, and Evaluation
University of Toronto

**Affiliated Research Scientist**
Centre for Global eHealth Innovation, Techna Institute
University Health Network
The Ubiquitous Health Technology Lab (UbiLab)
Public Health Surveillance

IoT and Mobile Health
EXTREME COLD
EXTREME AIR POLLUTION
PUBLIC HEALTH SURVEILLANCE
Wearables
THE HIDDEN IMPACT OF THE COVID-19 PANDEMIC
COVID-19

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

Emily A. Holmes,*, Ray C. O'Connor†, Vikash Patel, Janet Pease, Simon Wessely, Oliver Baldall, Helen Christensen, Roxanne Cohen Silver, Ian Creed, Tamara Ford, Ann John, Thomas Field, Kate King, Jim Madden, Susan Mohr, Andrea Pergaholk, Zoë Sharp,*, Anjana Summerville, Carol M. Worthman, Lucy Yardley, Katherine Cowan, Claire Cope, Matthew Hotopf†, Ed Bullmore†

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 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 mechanically 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 adopted 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 now and in the future. The pandemic is 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 now and in the future. The pandemic is occurring against the backdrop of increased prevalence of mental health now and in the future. The pandemic is occurring against the backdrop of increased prevalence of mental health now and in the future. The pandemic is occurring against the backdrop of increased prevalence of mental health now and in the future.
Working from Home
UNDERSTANDING THE IMPACT OF COVID-19
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 the map are the number of people in the age group who contributed data to the study.

*Data from the Fitbit community, March 16 - March 22, 2020.
Impact of COVID-19 on Sleep

Change in Sleep Minutes
Week Ending 3/22
Impact of COVID-19 on Sleep

The graph shows the average sleep minutes change from 2/9 to 3/29 for cities including Paris, Milan, Madrid, Barcelona, London, and Zurich. The trend indicates a significant increase in sleep minutes change over the weeks, with a noticeable peak towards the end of the period.
Impact of COVID-19 on Sleep

30 Million users worldwide
IMPACT OF COVID-19 ON HEALTH BEHAVIOURS
Smart Thermostat

ecobee
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).
Impact of COVID-19
Impact of COVID-19
Impact of COVID-19
Impact of COVID-19

2019

2020
Impact of COVID-19

Wake up time - 2020
Potential for Remote Monitoring

Behaviour Anomaly - 2020
GREATEST DATA CHALLENGES IN PUBLIC HEALTH RESEARCH AND PRACTICE
Lack Consistent Data Structure and 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-preserving data sharing programs.

**Consequences**

- Relevant data that could have a positive effect on public health practices is often unused.
Lack Consistent Data Structure an Data Repositories

Who Owns the Data? Open Data for Healthcare

Patty Kostkova1*, Helen Brewer2, Simon de Lusignan3, Edward Fottrell4, Ben Goldacre5, Graham Hart1, Phil Koczan6, Peter Knight7, Corinne Marsolier8, Rachel A. McKendry9, Emma Ross10, Angela Sasse11, Ralph Sullivan12, Sarah Chaytor12, Olivia Stevenson12, Raquel Velho13 and John Tooke14

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 citizens share data through mobile device-connected technologies), have great potential to contribute to our knowledge of disease, improving diagnostics, and delivery of healthcare.

Keywords: open data, data ownership, healthcare EPR, privacy, data policy
Big Data

The FOUR V’s of Big Data

Volume
- 40 ZETTABYTES of data will be created by 2020, an increase of 300 times from 2009

Variety
- It’s estimated that 2.5 QUINTILLION bytes of data are created each day
- Most companies in the U.S. have at least 100 TERABYTES of data stored

Velocity
- By 2016, it is projected there will be 18.9 BILLION NETWORK CONNECTIONS – almost 2.5 connections per person on earth

Veracity
- In one survey, 27% of respondents said they have enough data

Four Ways to Use Big Data

1. Profiling and Marketing: Target customers with personalized offers.

Sources:
- McKinsey Global Institute
- Survey: Cisco, Genentech, COM, SAS, IBM, MONETIC, DAS
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 hurdles in precision medicine and precision public health

Mattia Prosperi1*, Jae S. Min1, Jiang Bian2 and François Modave3

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 the study design and interoperability throughout all levels of the knowledge inference process, from the research semantics, to model development, and ultimately to implementation.
How to Address These Issues

**Solutions**

- Government + Industry + Academia Partnerships to establish trusted repositories.
- Combine the following (TRUST Principles (Lin et al., 2020):
  - Transparency (academia + government)
  - Responsibility (academia + government)
  - User Focus (academia + industry)
  - Sustainability (government + industry)
  - Technology (academia + industry)

**Example:**

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

How to Address These Issues

The TRUST Principles for digital repositories

Dawei Lin1,2, Jonathan Crabtree3, Ingrid Dillo4, Robert R. Downs5, Rorie Edmunds6, David Giaretta7, Marisa De Giusti8, Hervé L’Hours9, Wim Hugo8,9, Reyna Jenkyns10, Varsha Khodiyar11, Maryann E. Martone12, Mustapha Mokrane13, Vivek Navale14, Jonathan Petters15, Barbara Sierman16, Dina V. Sokolova16, Martina Stockhause17 & John Westbrook18

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, 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 with many other stakeholders involved, including researchers, funders, infrastructure, and service providers. Scientific data management is receiving increasing attention inside and outside of the scientific community, particularly in the contemporary Open Science discourse.
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/)
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.
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
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.

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

Stephen J. Mooney1 and Vikas Pejaver2

1Harborview Injury Prevention and Research Center, University of Washington, Seattle, Washington 98122, USA; email: sjm2186@uw.edu
2Department of Biomedical Informatics and Medical Education and the eScience Institute, University of Washington, Seattle, Washington 98109, USA; email: vpejaver@uw.edu

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 propose a taxonomy of sources of big data to clarify terminology and identify threads common across some subtypes of big data. Next, we consider common public health research and practice uses for big data, including surveillance, hypothesis-generating research, and causal inference, while exploring the role that machine learning may play in each use. We then consider the ethical implications of the big data revolution with particular emphasis on maintaining appropriate care for privacy in a world in which technology is rapidly changing social norms regarding the need for (and even the meaning of) privacy. Finally, we make suggestions regarding structuring teams and training to succeed in working with big data in research and practice.

Keywords

public health, big data, machine learning, privacy, training
Thank you!

Plinio Pelegrini Morita, PhD
@ plinio.morita@uwaterloo.ca
www.uwaterloo.ca/ubilab
@Plinio.Morita