

NEMODE
New Economic Models In The Digital Economy

Tracking biodata: SHARING AND OWNERSHIP



REPORT

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TRACKING BIODATA: SHARING AND OWNERSHIP

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REPORT ON RESEARCH PLACEMENT FUNDED BY THE RCUK DIGITAL ECONOMY NEMODE (NEW ECONOMIC MODELS IN DIGITAL ECONOMY) NETWORK.

INTRODUCTION

THIS REPORT PRESENTS AN OUTLINE OF THE MAIN RESEARCH ACTIVITIES, SHORT FIELDWORK AND KEY OUTPUTS THAT WERE UNDERTAKEN AND PRODUCED RESPECTIVELY DURING THE RESEARCH PLACEMENT (AS 2014 VISITING SCHOLAR) AT THE **RESEARCH CENTER SCIENCE AND JUSTICE, UNIVERSITY OF CALIFORNIA, SANTA CRUZ**. THE RESEARCH CONDUCTED DURING THE PERIOD OF THE GRANT (JANUARY - APRIL 2014) FOCUSES ON UNDERSTANDINGS OF PERSONAL DATA OWNERSHIP AND SHARING AMONGST INDIVIDUALS AND DIGITAL HEALTH START-UP COMPANIES WHO SELF-TRACK IN THE SAN FRANCISCO BAY AREA, AND DRAWS ON WIDER RESEARCH ON WEARABLE DEVICES FOR MONITORING HEALTH AND WELL-BEING. THE RESEARCH PLACEMENT WAS FUNDED BY THE **RESEARCH COUNCIL UK DIGITAL ECONOMY THEME**, UNDER THE NEMODE (NEW ECONOMIC MODELS IN THE DIGITAL ECONOMY) NETWORK.

OBJECTIVES

The objective of the research was to examine issues of privacy and personal data ownership in the Digital Economy, and particularly in relation to digital health and personal data tracking, within the context of fast moving developments that are taking place in high-tech hubs in California.

To meet these objectives, interviews and participant observation were conducted in order to map:

(A) POTENTIAL NEW MODELS OF PERSONAL DATA MANAGEMENT BY INDIVIDUALS AND START-UP COMPANIES;

(B) POLICY AND SOCIAL IMPLICATIONS OF SUCH A NEW MODEL OF DATA OWNERSHIP AND SHARING;

(C) CREATE A NETWORK BETWEEN ACADEMICS, NON-GOVERNMENTAL ORGANISATIONS AND SILICON VALLEY START-UP COMPANIES, WHICH WILL ENGAGE WITH THESE QUESTIONS.

BACKGROUND

BUSINESSES, HEALTHCARE COMPANIES, AND GOVERNMENTS increasingly invest in harvesting, aggregating and using Big Data, which makes Big Data a necessary new field for social research. Big Data is still a contested term, and indeed a problematic one (Boyd and Crawford 2012), as 'small data' approaches to social research have shown (Stephansen and Couldry 2014). At the same time, academic researchers, particularly in the biomedical sciences, turn to the internet as it provides the promise of a huge collection of datasets. These developments raise important questions about the value of personal data, and there is clear need for public debate and regulation concerning the control of personal data. More specifically to the focus of this project, many start-up companies currently develop applications that track personal data, both for health and fitness purposes, and for a variety of audiences (healthcare administration, consumer, wearable companies, employers etc). At the same time, individuals and communities, such as the *Quantified Self*, try to make sense of these data and the legal and ethical frameworks that surround them. During the placement, a series of interviews were conducted, that addressed questions of sharing, ownership and value of personal data.

EXECUTIVE SUMMARY

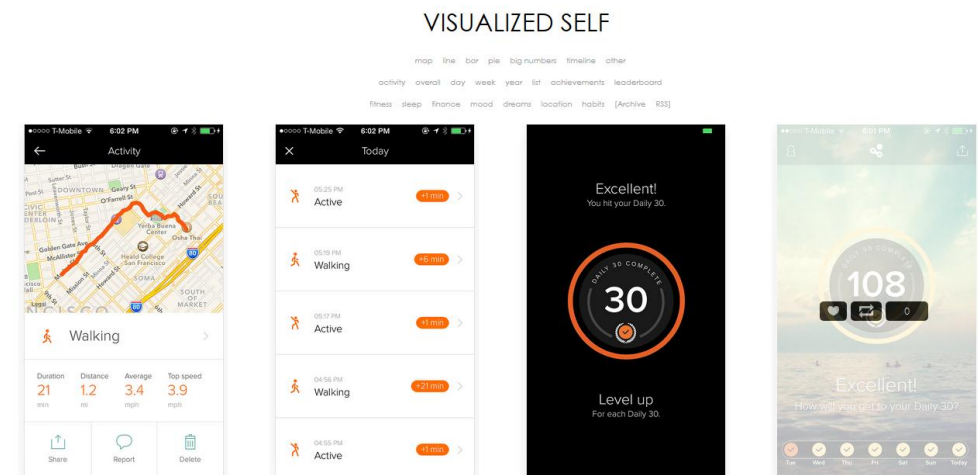
People who use self-tracking for health or wellbeing purposes in their everyday life are often inclined to share their personal data with others. Social media (Twitter, weblogs) are predominately used for sharing visualisations and reports of data, whereas increasingly new social spaces are created, such as forums and specialised online platforms, where information about hacking into personal data is exchanged (e.g. Fitbit, Quantified Self discussion forum, Patients Like Me). The material collected through interviews and participation in various events during this research placement indicates that:

- ❖ The motivation behind sharing information with others is often learning: sharing personal data enables the production of knowledge about shared medical conditions, concerns or interests, and it also enables the development of technical skills (self-hacking).
- ❖ Individuals who track and self-quantify are sceptical about the use of their personal data by companies and third parties without their consent, and are wary about who will have access to their data in the future. However, the concerns associated with the collection, ownership and sharing of data change considerably when we move from tracking for pleasure and self-improvement for fitness, to tracking for health by patients and caregivers.
- ❖ The services provided by self-tracking start-ups seem to be heading towards an iterative reduction of data, in other words towards showing less information and in the form of reports, rather than the entire cohort of the data collected, which is hoped to make the analysis of data more meaningful.

KEY ACTIVITIES DURING PLACEMENT

CONTRIBUTIONS TO THE PROJECT

DURING THE PLACEMENT, the PI Dr Aristeia Fotopoulou was in conversation with a number of organisations, companies and individuals. Contact involved networking activities, participation in meetings, and collection of research material (qualitative interviews, participant observation, web analysis):



- **INSTITUTE FOR THE FUTURE**

Based in Palo Alto California, this non-profit research centre specializes in long-term forecasting, and quantitative futures research methods. Dr Aristeia Fotopoulou was in contact with Adam Elmaghraby, Research Director of the *Health Horizons* and *Health + Self* research strands. She also attended the panel discussion **Ageing Forward: Exploring the Future of Caregiving & Technology**, on February 26, 2014, which provided useful insights about the importance of self-logging by both patients and carers for the future of caregiving.

- **NOTUBE**

Tele-medical spin-off-company of the Medical University of Graz, Austria, who works in close co-operation with the Medical University of Graz as well as the Society for telemedicine and e-Health. The Medical University of Graz supports NoTube in medically challenging cases with their specialized professional staff. Dr Aristeia Fotopoulou was in contact with CEO Samuel Scheer.

- **HUGO CAMPOS**

Interview with a heart patient and member of the Quantified Self, who has attempted to hack his pacemaker. The interview helped gain better understanding in regards to self-tracking for people with life threatening conditions and whose motivation is health.

- **QUANTIFIED SELF, SAN FRANCISCO BAY AREA**

Involvement with the *Quantified Self San Francisco Bay Area* comprises of networking activities, participant observation and qualitative interviews. Key individuals who were in conversation with Dr Fotopoulou are: Ernesto Ramirez (Quantified Self Labs, interview), Gary Wolf (co-founder of Quantified Self), and Kate Farnady (Development Director and co-organiser of QSXX San Francisco).

- **PROJECT ADDAPP**

Project AddApp (addapp.io) is a start-up launching a platform that integrates and analyses all fitness data from multiple apps (e.g. Fitbit, mapmyrun, Ihealth, sreava, and so on). Dr Fotopoulou was in conversation with developer Kouris Kalligas about the implications of app integration for gathering personal data and about the data privacy policy of the company.

- **METROMILE**

MetroMile (Metromile.com) is an iPhone app and car insurance start-up that uses a sensor attached to track driving stats, monitor the car engine's health, and access smart services. Dr Fotopoulou was updated by Chloe Fan, User Experience Designer.

- **EXOGEN BIOTECHNOLOGY**

Exogen Biotechnology (exogenbio.com) is a health start-up aimed at developing cutting-edge technologies for individuals to monitor damage to their DNA and to assess their DNA repair capacities for the purposes of personalized and preventive health care. Exogen's technological platform for assessing DNA damage and repair capacities was developed at the Lawrence Berkeley National Laboratory by a team of scientists and engineers. Exogen was founded in 2012 to translate this new technology to enable rapid processing of human blood specimens and to make testing services affordable and accessible to the public. Dr Fotopoulou was informed about the start-up by the Team Members and posed questions about the data privacy policy of the company.

- **HUMAN**

Human (human.co) is a fitness start-up that uses sensors in mobile phones to track daily activity, while it aims to motivate users to work out for minimum 30 minutes per day. It automatically categorises outdoor activities like walking, running, biking, whereas all other

exercise is be identified as 'Active'. Dr Fotopoulou interviewed CEO Renato Valdes Olmos about data privacy and ownership, data visualisation, the digital start-up landscape and the mission statement of company.

- **MIKE McDEARMON**

Dr Fotopoulou interviewed Design Technology Specialist Mike Mc Dearmon (mikemcdearmon.com), based in New York City, about self-tracking, design research, user experience, and 3D visualization.

- **WHITNEY ERIN BOESEL (QUANTIFIED SELF BOSTON)**

Dr Fotopoulou interviewed academic researcher Whitney Erin Boesel about her experience of researching the Quantified Self, and discussed future research collaborations.

- **EMPOWER INTERACTIVE, INC.**

EMPOWER'S web and mobile tools teach core concepts of cognitive-behaviour therapy (CBT) to address the root of behavioural health problems. Dr Fotopoulou interviewed Eve Phillips, CEO, an experienced Silicon Valley product builder, entrepreneur and investor, and gained valuable understanding on the company's core values and user experience.

- **AGING 2.0**

Dr Fotopoulou connected with Aging 2.0 (www.aging2.com), a start-up networking organisation that supports entrepreneurs working to enhance the lives of older adults and improve long-term care. They provide strategic advice and access to mentors, pilots and capital for a small number of high-potential, early-stage companies, and organise events Supported by Home Instead, the Institute on Aging, AgeTech West, Cambia Health Solutions, ClearCare, Stanford Center on Longevity, Wilson Sonsini Goodrich & Rosati and Dan Reider Design.

- **ROCK HEALTH**

Dr Fotopoulou connected with Rock Health (www.rockhealth.com), a San Francisco based organisation that funds and supports digital start-ups building the next generation of technologies transforming healthcare.

- **LAUNCH FESTIVAL 2014, SAN FRANCISCO**

Launch Festival is a technology start-up festival and hackathon (launch.co). Dr Fotopoulou attended the fitness and digital health start-up talks.



Image: Mike McDearmont's integrated data visualisation

"We need to make sure patients are comfortable sharing information and know what happens to it when they do" @RainaMerchant #GreatChallenges (Twitter, 25 February 2014

CONTRIBUTION TO THE ACTIVITIES OF THE HOST ORGANISATION, UNIVERSITY OF CALIFORNIA SANTA CRUZ.

DURING THE NEMODE RESEARCH PLACEMENT, Dr Fotopoulou liaised with faculty, postgraduate students and research fellows based at the **Center for Science and Justice**, and attended research events and seminars organised by the Center. On January 22, 2014, she attended the *MEETING OF BIOMEDICAL PRIVACY AND GENOMIC OPENNESS*, a conversation about the unresolved issues raised by the recent push to expand efforts to collect and aggregate biological samples and data. Jenny Reardon (Science & Justice Research Center Director and Associate Professor of Sociology) facilitated a conversation between Peter Yu (incoming President of the American Society of Clinical Oncology and Director of Cancer Research (ASCO) at the Palo Alto Medical Foundation) and David Haussler (Director of the UCSC Center for Biomolecular Sciences and Engineering).

On February 5, 2014, the **Center for Cultural Studies** invited Dr Fotopoulou to give a talk about her NEMODE funded research in progress. The working paper entitled '*ALL THESE EMOTIONS, ALL THESE YEARNINGS, ALL THESE DATA*': *PLATFORM OPENNESS, DATA SHARING AND VISIONS OF DEMOCRACY* is the basis for a forthcoming peer-reviewed journal article which observes the emerging mediascape of wearable sensors and mobile technologies through utopian and dystopian narratives, and makes special mention to the *Quantified Self* culture. Moving beyond the Panopticon model and questioning the notion of empowerment, the paper suggests that analysing user practices in specific locations can help us understand how the changing role of data in everyday life is symptomatic of shifts in the relationship between citizens and the state.

On February 19, 2014 the **Art Department** Chair Jennifer Parker and [UCSC OpenLab](#) invited Dr Fotopoulou to give a talk [about her work on the current landscape of wearable sensors and digital culture](#). The presentation was mainly addressed to postgraduate and PhD students of the *DIGITAL ARTS* programme, who are currently developing a collaborative art installation in which they plan to employ wearable sensors. For this session, Dr Fotopoulou discussed her current fieldwork in Silicon Valley and San Francisco, and presented part of a media analysis of *Fitbit*, a cloud-based fitness tracking device, and discussed emerging self-management behaviours - this work is part of collaborative research undertaken for the EU-funded EPINET project, and will be presented in detail in a jointly authored forthcoming peer-reviewed publication. A Q&A followed, where students and researchers had the opportunity to ask detailed questions about wearable devices, and the critical issues around their use. The experience opened up the material for discussion to artists. It also enabled Dr Fotopoulou to develop a connection with the Digital Arts Department in UCSC, whereas plans for further collaborations (joint publication) were also discussed.

On February 28th 2014, Dr Fotopoulou was invited to participate in a panel discussion with bioartist **Oron Catts** (synthetica) and philosopher Jake Metcalf. The event was hosted by Andy Murray and Sophia Magnone and was part of *JUSTICE IN A MORE THAN HUMAN WORLD – COLLABORATION OR EXPLOITATION? WORKING WITH LIVING SYSTEMS ACROSS THE ARTS AND SCIENCES*, by Science and Justice Workgroup [Human / Non-Human Collaboration across the Arts & Sciences](#). She presented collaborative research on the in-vitro meat case of the [EPINET project](#). The paper is an analysis of the live television launch of the first in-vitro meat burger in August 2013, which frames the launch as a “media event” (Couldry & Hepp); and an examination of the main discourses circulating in digital culture round this time, which together work towards a critical discussion about the publics of synthetic meat.

OUTPUTS AND IMPACT

THE PROJECT TRACKING BIODATA FITS THE RESEARCH COUNCILS UK DIGITAL ECONOMY THEME AS IT PRODUCED RESEARCH FINDINGS WHICH CAN INFORM THE DEVELOPMENT OF POLICY AND BE USED BY SCHOLARS AND COMPANIES INTERESTED IN NEW ECONOMIC MODELS AND THEIR RELATIONSHIP TO THE DIGITAL ECONOMY. DURING THE PLACEMENT, THE PI DR **FOTOPOULOU** LINKED WITH SCHOLARS AND COMPANIES, WHOSE RESEARCH INTEREST IS TRANSFORMATIONS BROUGHT BY DIGITAL TECHNOLOGIES IN THE AREA OF HEALTH/FITNESS RESEARCH. THIS PROJECT WILL FURTHER PRODUCE EXCELLENT RESEARCH OUTPUTS, WHICH IMPACT ON THE GROWTH, PROSPERITY AND WELLBEING OF THE UK, TARGETED TO THE WIDER PUBLIC, DIGITAL START-UPS (BUSINESS) AND ACADEMIC FIELDS.

IN PARTICULAR, RESEARCH MATERIAL COLLECTED DURING THIS PLACEMENT WILL BE ANALYSED, WRITTEN-UP AND PRESENTED IN THE FOLLOWING FORMATS:

- ✓ **Participation now** section of **Open Democracy** (e-magazine) commissioned Dr Fotopoulou and will publish a piece about the *Quantified Self*. Participation now is a platform co-ordinated by the Open University, which aims to facilitate debate and mutual learning among the many different actors involved, so that we better understand these new forms of public participation in the broader social and political context in which they are situated.
- ✓ **The Conversation:** Curated by professional editors, *The Conversation* offers informed commentary and debate on the issues affecting our world.
- ✓ Academic Paper entitled ***Quantifying the Self: All these emotions, all these yearnings, all these data*** has been accepted by the Academic Committee of the *10TH INTERNATIONAL CONFERENCE CROSSROADS IN CULTURAL STUDIES* that will be held in Tampere, Finland, July 1-4, 2014. This allows further dissemination of the research and public engagement.

- ✓ The project **website** (<https://trackingbiodataproject.wordpress.com/>) and Twitter account (@aristeaf) raised awareness to a wider public and were used to disseminate the findings of the research in a way that interested parties were able to understand and use.
- ✓ **Graduate student involvement:** The Master's students of the *Department of Media and Film, University of Sussex*, as part of a workshop led by Dr Fotopoulou on November 1st, 2013 on *DIGITAL METHODS: WEB MAPPING OF CONTROVERSIES*, researched the issue of personal data sharing. Students were divided into three groups and compiled a list of web key actors in this online discussion, and then used visualisation tools to map them.
- ✓ Peer-reviewed journal article in high-ranking journal (forthcoming).

PERSONAL DEVELOPMENT SUMMARY: BENEFITS OF THE PLACEMENT FOR THE RESEARCHER

THE PI DR FOTOPOULOU IS AN EARLY-CAREER RESEARCHER, with expertise in digital media and culture, and with an interest in the sociology of emerging technologies. Currently based at the Department of Media and Film, University of Sussex, she works as postdoc research fellow in the European Commission funded project EPINET (FP7-SCIENCE-IN-SOCIETY-2012), on a media analysis of three emerging technologies – smart grids, wearable sensors and in-vitro meat. In March 2013, acting as CI for the CCN+ network *SUSTAINING NETWORKED KNOWLEDGE*, she visited the US with funding from the British Consulate, as member of a team which sought to undertake knowledge exchange, make new contacts and explore possibilities for collaboration via research projects. She then made contacts with leading actors in the field of digital & biotechnological innovation, including GigaGen Inc. and Genomera, and initiated a basic network with Silicon Valley companies and UCSC.

As the list of activities demonstrates, the 2014 placement helped Dr Fotopoulou create and further cultivate partnerships with business partners, academic partners, non-governmental organisations and individuals, and enabled the researcher to begin building an independent research profile and scholarship in the sociology of self-tracking and wearables for health and wellbeing. She was also able to develop an extensive network of connections in the San Francisco Bay Area, Silicon Valley and Santa Cruz, California. These connections will be instrumental for Dr Fotopoulou's further career, as they enable access to a nascent research field.

During the placement Dr Eleftherios Zenerian was employed as **Research Assistant** in this project and contributed an up-to-date bibliography on self-tracking and on self-quantification, and to setting up the website. Employing as RA helped the PI gain basic supervision and project management skills, which are important for career advancement purposes. It helped Dr Zenerian to gain experience and develop research and admin skills, and move in a Research Fellow position.

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