
Digital Health & Self-experimentation: Design Challenges & Provocations

Markéta Dolejšová

Communication and New Media
Department
National University of Singapore
marketa@u.nus.edu

Denisa Kera

School of Art & Design, Prague
College, Czech Republic
denisa.kera@gmail.com

Cristiano Storni

Interaction Design Centre,
University of Limerick, Ireland
cristiano.storni@ul.ie

Rohit Ashok Khot

Exertion Games Lab,
RMIT University, Australia
rohit@exertiongameslab.org

Ivan John Clement

MSD IT Innovation Hub, Singapore
ivanjohn.clement@gmail.com

Inka Pavelka

MSD IT Innovation Hub, Singapore
inka.pavelka@gmail.com

Puneet Kishor

Glenshaw Associates, USA
punk.ish@gmail.com

Abstract

Quantified self-experimentation with personal health is a growing activity among health enthusiasts, biohackers, and patients with chronic conditions. By collecting and sharing their health data through self-tracking devices and health networking services, self-experimenters engage in a unique form of $n=1$ citizen science-style research. This data sharing altruism is constrained by limited data security, validity, and socio-economic access. We will explore these issues as design challenges. The workshop invites various stakeholders (private, corporate, non-profit, academic) to engage in a discussion and a performative prototyping of a design framework for transparent and just health self-experimentation.

Author Keywords

Digital Health; Self-experimentation; Self-tracking;
Citizen Science; Quantified Self

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g.,
HCI): Miscellaneous

Permission to make digital or hard copies of part or all of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for third-party components of this work must be honored. For all other uses, contact the Owner/Author. Copyright is held by the owner/author(s).

CHI'17 Extended Abstracts, May 06-11, 2017, Denver, CO, USA
ACM 978-1-4503-4656-6/17/05.
<http://dx.doi.org/10.1145/3027063.3027071>

Online self-experimentation venues:

¹ **Quantified Self**

<http://quantifiedself.com/>

² **The Quantified Body**

<http://thequantifiedbody.net/>

³ **Soylent Discourse**

<http://discourse.soylent.me/>

⁴ **Longecity**

<http://www.longecity.org/>

⁵ **Biohack.me**

<http://biohack.me/>

⁶ **PatientsLikeMe**

<http://www.patientslikeme.com/>

⁷ **23andMe**

www.23andme.com/

⁸ **Ubiome**

<http://ubiome.com/>

⁹ **MyMicrobes**

<http://my.microbes.eu/>

Background

Quantified self-experimentation with personal health enables individuals to collect, analyze, share and act upon a range of data about themselves through $n=1$ (single-subject) trials. Physical and cognitive functions such as body weight, athletic performance, sleep quality or mood can be monitored and experimented with using self-tracking devices, consumer genomic and microbiomic services, and online health networks. This creates new opportunities for a unique form of a citizen science-style research participation [4,14].

Probably the most popular self-experimentation platform, the Quantified Self (QS)¹, enables enthusiasts to share their quantified self-tracking projects via online forum discussions and internationally-distributed meetup groups. Besides the QS network, there is a variety of other smaller forums, podcasts and wikis dedicated to self-experimentation, such as The Quantified Body podcast,² or the Soylent forum³ discussing personalized powdered diets. There are also groups of more extreme biohackers and transhumanists experimenting with their bodies beyond the 'normal' healthy states. Users of Longecity⁴ and Biohack.me⁵ share their findings from experiments with nootropics, psychedelics microdosing, or subdermal sense-enhancing implants.

While the QS and biohacking groups rely mostly on self-governance, there is also hybrid model of expert-amateur communities run by academic and healthcare institutions or crowd-funded health ventures using professional lab equipment. These include, for instance, the PatientsLikeMe platform⁶ where users aim to resolve their diagnosed health conditions by sharing their medical records and discussing possible treatments [16]. Self-experimentation activities of both

patients and health enthusiasts are often supported by direct-to-consumer (DTC) genomics and microbiomics services such as 23andMe⁷, Ubiome⁸, or My.microbes⁹. Users can share, discuss, and act upon their results while being invited to contribute not only to their personal improvement, but also to the advancement of participatory healthcare and citizen science [4,6].

Motivation and Goals

The growing popularity of health self-experimentation raises many hopes and fears related to the future uses of health data. Advocates mention numerous advantages, such as the low processing costs and greater velocity of hypotheses, as compared to the conventional health studies [9,12]. As shown by [6] or [17], hands-on engagement with personal health and peer support in the communities can also have a positive impact on participants' scientific literacy, self-understanding, and emotional wellbeing. However, there are also certain limitations that curb these celebratory accounts, such as the low scientific validity of $n=1$ experiments [4]; safety risks of self-guided health interventions [2,15]; ambiguous privacy aspects of open data sharing [4,14]; and limited socio-economic access to technology and knowledge resources [7,13].

These issues are mostly related to the multiplicity of self-experimentation stakeholders pursuing diverse and sometimes conflicting goals. Apart from self-experimenting practitioners, the stakeholders include commercial app developers, citizen science-like enterprises, and corporate healthcare providers who may seek for (citizen) science and healthcare advancement, as well as financial profit [1,5]. The strong asymmetry in terms of who uses the benefits

¹⁰ Schedule of activities (1 day workshop)

9am-9:15	Welcome & introductions by organizers
9:15-10	Introductions of participants and proposals
10-12pm	Hands-on self-tracking & discussion
12pm-1	Lunch
1-2pm	"Post-lunch" self-tracking & discussion
2-5pm	Break out into groups, work on design scenarios and prototypes to envision systems around the identified themes and issues
5-6pm	Groups report back and showcase design ideas; final wrap-up and synthesis

from the health data sharing platforms is the main problem we will address within the workshop. The workshop participants representing various stakeholder groups will be invited to reflect upon their perspectives, interests, and affiliations in health self-experimentation through performative and hands-on activities. The organizers themselves have very diverse theoretical and experiential backgrounds, which will help guide these activities and also drive the participants' selection process. Our main goal here is to define future participatory models of health data sharing services that will better respond to the concerns and ideas raised during the workshop. We hope to collectively reach a design framework for transparent, just and responsible health self-experimentation practices.

Workshop Structure

We want to test a performative model of stakeholder discussions using design scenarios, prototypes, and mockups of future health data sharing services while also collecting our own health data in real time. During the workshop, we will monitor our heart rates, pulses, and emotional or stress levels via various self-tracking devices brought by organizers. The activities¹⁰ will be further prompted through discussion over organizers' personal health datasheets (e.g. 23andMe and Ubiome results; Soylent diet logs). Participants (up to 20 people expected) will also be invited to bring their own existing records. This performative model for managing stakeholders' perspectives will help us create a more detailed categorization of their different concerns, hopes and fears in respect to the different design ideas and principles. The hands-on data collection and sharing will also enable us to experience personally some of the dilemmas behind self-monitoring and self-

experimentation on which we will reflect through following themes.

Workshop Themes, Provocations and Design Challenges

The workshop activities will revolve around three leading themes comprising of "provocations" and "design challenges".

Theme I: Validity and reliability issues

Provocations:

The data practices in current self-experimentation projects rarely meet the standards of rigorous scientific research. Amateur self-experimentation studies are not randomized or blinded as in traditional clinical studies and often lack coherent data collection protocols [4,8]. The data analysis and evaluation of findings is usually not subjected to a proper peer-review and rely on unstructured advice provided in online forums or meetups [1,8]. That brings in the issue of limited scientific validity, which creates potential health risks for practitioners and weakens the acceptability of n=1 findings by health professionals. However, we would also like to question the very assumption that the expert way of knowing is always superior to that of amateurs. Would we lose some surprising and potentially valuable findings from peer-validated self-experiments by pushing for more disciplined data sharing practices? Should we only aim for the professionalization of amateur self-experimentation, or rather promote an agnostic approach to design that does not assume the superiority of one form of knowledge over another [11]?

Design challenges:

How can design solutions (interfaces, activities, tools) increase the adherence to more structured research

protocols and baseline measures for data collection and evaluation? Could these protocols be crowdsourced, co-designed, and agreed upon by the community members, while ensuring scientific validity? How can we design tests comparing amateur and professional data collection? What are the circumstances under which the amateur data becomes acceptable to some of the large public health bodies?

Theme II: Security and privacy issues

Provocations:

The data sharing practices in online health communities often benefit to corporate stakeholders rather than to the end users, which brings in certain privacy issues. Even the self-governed communities such as QS or Soylent that started as independent hobbyist endeavors often end up adopting a business ethos and monetizing the data shared over their services and products [1,3]. While some suggest that all interested stakeholders could still benefit from such data sharing [1,12] potential exploitation of users privacy is an important concern [5,13]. Who can access and (re)use what type of data and to what end? Should we accept the idea of data sharing altruism and donating data for good as an intrinsically virtuous practice?

Design challenges:

How can design help to balance altruistic data sharing intentions with market-led goals? Can design support transparent systems for data exploration that leaves interpretive control with the end users? How can we manage archival of the data and mitigate potential misuses by nefarious third parties? Should the design support further opening of self-experimentation data

for professional health and pharmaceutical research at all?

Theme III: Socio-economic access

Provocations:

Self-experimenters usually pay for their self-tracking devices, DTC sequencing tests, and participation in crowdsourced health studies, which makes these services affordable only to certain socio-economic cohorts [7]. For instance, the QS and Soylent groups are populated mostly by middle-aged white males [2,7]. Not only does this skewness exacerbate the already problematic healthcare disparities, but it also limits the idea of crowdsourced health studies and trials as a source of demographically robust data [12]. Thus, the limited access and demographic skewness are concerns both within the communities and on a broader social scale.

Design Challenges:

How can design support social robustness of self-experimental healthcare? Can design bring the self-experimentation practices closer to participatory models of design and support a "genuine participation" [10]?

Pre-Workshop Plans

We will disseminate the workshop open call over the workshop website www.digitalhealth.science and other CHI-related channels. The website will include links to organizers' projects relevant to the themes, as well as projects proposed by accepted participants. We are also involved in organizing a food printing course at CHI 2017 and we will ask the course participants to spread

the word about our workshop and also participate themselves. During the workshop we will use standard social media tools (Twitter, Facebook, Instagram, etc) to document the activities in near-real-time.

Post-Workshop Plans

We will focus on ensuring an ongoing discussion and sharing of resources among workshop participants and other interested parties. This will comprise of scenarios, prototypes, and other media content (images, video, text documentation) created during the workshop to be shared on the workshop website. Organizers will also upload a follow-up report on the workshop outcomes. To extend the outcomes of workshop activities to the wider HCI audience, we will invite selected participants to contribute towards a special issue on health self-experimentation of a leading HCI / STS journal.

Organizers

Markéta Dolejšová (*main contact person for this workshop*) is a PhD Candidate in the Communication and New Media at National University of Singapore, specializing in health and diet self-experimentation in citizen science communities. She has published in HCI venues including CHI and CSCW, and organized workshops on food and diet experimentation at conferences, hackerspaces, and art venues globally. She runs several critical food design projects exploring themes around human-food interaction, data edibilization, and food design for social good.

Denisa Kera is a philosopher and designer working on open science, DIYbio, and various citizen science projects. She is part of the Hackteria.org network, a community of scientists, artists and designers interested in open hardware for science projects

especially in the Global South. Currently she is on parental leave and works part time as adjunct professor in the MFA programme in Future Design, Prague College, and in the New Media studies programme at Charles University. Before July 2016 she was an Assistant Professor at the National University of Singapore and Asia Research Institute research fellow.

Cristiano Storni is a Lecturer in Interaction Design and Director at Computer Science and Information Systems department, University of Limerick. He holds a PhD in Information Systems and Organization from the Faculty of Sociology in the University of Trento. His research lies at the intersection of Science and Technology studies and Interaction/participatory research. His current research concerns design theory and practices, the social shaping of technology especially ICT (with an interest on the notions of appropriation, participation, and empowerment) and in different application areas: Health Care, Web2.0, open hardware and software, and social innovation. In the healthcare domain, he focuses on self-care practices and technology in the context of chronic and less-known disease (especially type 1 Diabetes). In the design area, he is currently working on the 'coming together' of design (participatory and interactive) and Actor Network Theory.

Rohit Ashok Khot is a PhD candidate in the Exertion Games Lab at RMIT University. His PhD research utilizes emerging technologies such as 3D printers and food printers to orchestrate new design strategies for making physical activity more memorable, enjoyable and fulfilling. His work has received numerous accolades that include best paper and honorable mention awards, a prestigious IBM Research PhD

fellowship and key media mentions. Rohit also serves on program committees for reputed conferences like TEI, DIS and CHI WiP.

Ivan John Clement is a data scientist with Merck & Co. (MSD), focused on applying advanced analytics on next-generation sequencing and -omics data, health economics read-outs, and novel forms of real-world evidence. He has held research attachments with the Massachusetts Institute of Technology (MIT), the Singapore-MIT for Research and Technology (SMART), and the Mechanobiology Institute, working on projects ranging basic cancer pathophysiology to mobile- and cloud-enabled health data collection and analysis. He was formerly a computational scientist with Eli Lilly and Company, building computational models of human clinical trials and supporting report submissions to authorities such as the FDA.

Inka Pavelka is a senior program manager with Merck & Co. (MSD), spearheading the company's academic-industry engagement efforts in the IT space. She is part of the pioneer group of change-agents executing on Merck's "Innovation Hub" concept - a network spread across US, Europe, and Asia designed to enable digital health transformation and access to IT innovation. As part of the "Innovation Hub" concept, she has designed and organized the Singapore Grand Challenge - a co-creation event with student groups from Singapore universities around digital health. She was formerly with Sun Microsystems, working on semantic web projects.

Puneet Kishor is an open science and data advocate based in Washington DC, Paris and Mumbai. He is a member of Plazi, a Swiss non-profit dedicated to

freeing structured data from taxonomic literature, and a visiting scientist at the Homi Bhabha Center for Science Education, Mumbai. Until recently, Puneet was the Manager of Science and Data Policy at Creative Commons, a San Francisco-based NGO with a mission to realize the full potential of the internet through tools that permit open licensing. He believes in "open by default" and works toward a scenario where private data may be used for public good within the prevailing norms and regulations of ethics and privacy.

Call for Participation

Quantified self-experimentation with personal health is a growing activity today. By collecting and sharing personal health data through self-tracking devices and health networking services, self-experimenters engage in a unique form of $n=1$ citizen science-style research. This data sharing altruism is constrained by limited data security, validity, as well as socio-economic access – issues that we will explore as design challenges. The workshop invites HCI/STS researchers, practitioners, healthcare professionals, as well as corporate actors interested in the self-experimentation domain.

Themes, provocations and design challenges:

(details at: www.digitalhealth.science)

- **Provocation I:** The data practices in self-experimentation projects rarely meet the standards of rigorous scientific research.
- **Design challenge:** How can design solutions (interfaces, activities, tools) increase the adherence to more structured research protocols and baseline measures for data collection and evaluation?

- **Provocation II:** Data sharing practices in online health communities often benefit to corporate stakeholders rather than to the end users. That brings in certain privacy issues.
- Design challenge: How can design help to balance the altruistic data sharing intentions with the market-led goals? How to manage archival of the data to mitigate potential misuses by nefarious third parties?
- **Provocation III:** Self-experimentation services are affordable only to certain socio-economic cohorts.
- Design challenge: How can design support social robustness of self-experimental healthcare?

Proposals (4 pages max) should include scenarios, prototypes or mockups of future health data sharing practices, as well as ideas for creative hands-on activities to be conducted during the workshop. Proposals will be selected based on their originality and quality, and may be mailed to marketa@u.nus.edu. Participants will introduce their proposals during a round table discussion. Proposals will be further activated through hands-on self-tracking activities, scenario building, and prototyping around the identified themes. Participants (up to 20 people to be accepted) are also welcomed to suggest other previously unmentioned themes, provocations, and challenges.

References

1. Kristen Barta and Gina Neff. 2016. Technologies for Sharing: lessons from Quantified Self about the political economy of platforms. *Information, Communication & Society* 19, 4, 518-531.
2. Markéta Dolejšová. 2016. Deciphering a Meal through Open Source Standards: Soylent and the Rise of Diet Hackers. *Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems*, Santa Clara, California, USA.
3. Markéta Dolejšová and Denisa Kera. 2017. Soylent Diet Self-Experimentation: Design Challenges in Extreme Citizen Science Projects. Full paper to appear in proceedings of Computer Supported Cooperative Work (CSCW) 2017 conference.
4. Carine Gimbert and François-Joseph Lapointe. 2015. Self-tracking the microbiome: where do we go from here? *Microbiome* 3, 1, 1.
5. Suneel Jethani. 2015. Mediating the body: Technology, politics and epistemologies of self. *Communication, Politics & Culture*, Vol. 47, No. 3, 2015: [34]-43.
6. Stacey Kuznetsov, Aniket Kittur, and Eric Paulos. 2015. Biological Citizen Publics: Personal Genetics as a Site of Public Engagement with Science. In *Proceedings of the 2015 ACM SIGCHI Conference on Creativity and Cognition (C&C '15)*. ACM, New York, NY, USA, 303-312. DOI=<http://dx.doi.org/10.1145/2757226.2757246>
7. Victor R Lee and Mary Briggs. 2014. Lessons learned from an initial effort to bring a quantified self meetup experience to a new demographic. In *Proceedings of the 2014 ACM International Joint Conference on Pervasive and Ubiquitous Computing: Adjunct Publication ACM*, 707-710.
8. Gina Neff and Dawn Nafus. 2016. *The Self-Tracking*. MIT Press.
9. Seth Roberts. 2010. The unreasonable effectiveness of my self-experimentation. *Medical hypotheses* 75, 6, 482-489.
10. Toni Robertson and Jesper Simonsen. 2012. Participatory Design. *Routledge international handbook of participatory design*, 1.

11. Cristiano Storni. 2015.. Notes on ANT for designers: ontological, methodological and epistemological turn in collaborative design. *CoDesign*, 11(3-4), 166-178.
12. Melanie Swan. 2012. Crowdsourced health research studies: an important emerging complement to clinical trials in the public health research ecosystem. *Journal of medical Internet research* 14, 2, e46.
13. Sandra Vamos and Klaus Klein. 2016. Our self-tracking movement and health literacy: are we really making every moment count? *Global Health Promotion*, 1757975916660674.
14. Effy Vayena and John Tasioulas. 2015. "We the Scientists": a Human Right to Citizen Science. *Philosophy & Technology* 28, 3, 479-485. DOI=<http://dx.doi.org/10.1007/s13347-015-0204-0>.
15. Allen B Weisse. 2012. Self-experimentation and its role in medical research. *Texas Heart Institute Journal* 39, 1, 51.
16. Peter West, Richard Giordano, Max Van Kleek, and Nigel Shadbolt. 2016. The Quantified Patient in the Doctor's Office: Challenges & Opportunities. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*. ACM, New York, NY, USA, 3066-3078. DOI=<http://dx.doi.org/10.1145/2858036.2858445>
17. Kaiton Williams. 2015. An anxious alliance. In *Proceedings of The Fifth Decennial Aarhus Conference on Critical Alternatives Aarhus University Press*, 121-131.