

Mad Price Ball

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Current position

2017- Executive Director and President, [Open Humans Foundation](#)

Additional affiliations

2018- Director: MyData Global <https://mydata.org/>

2014- Collaborator: Human-Computer Interaction for Personal Genomics
<http://cs.wellesley.edu/~hclilab/pghci.html>

Previous affiliations & education

2017-2019 Fellow, [Shuttleworth Foundation](#)

2015-2018 Collaborator, [PeopleSeq Consortium](#)

2015-2017 Director of Research, Open Humans Foundation (named PersonalGenomes.org until 2016)

2014-2015 Senior Research Scientist, PersonalGenomes.org

2010-2016 Director of Research, Harvard Personal Genome Project

2010-2014 Postdoctoral Researcher, George Church laboratory at Harvard Medical School.

2010 Ph.D. in Biophysics, Harvard University.

2002 B.S. in Biology, California Institute of Technology.

Current work

My work focuses on enabling people to access, use, and share their health and personal data to advance individual understanding, collective empowerment, and research. This work primarily occurs through [Open Humans](#) and the associated nonprofit, [Open Humans Foundation](#).

Open Humans combines technology and community to advance an open and participant-centric approach to human subjects research. By working with the individuals who are contributing to research, we can enable new ways to share data and new approaches to doing science. My work also extends to related areas in N-of-1 and participant-led research, open science, and advocacy.

Invited Speaking

- 2018 Speaker, “A Self-Study of My Child’s Genetic Risk”, at [2018 Quantified Self Conference](#).
- 2018 Speaker, “From Personal Data to Collective Power”, main stage in the “Collective and Personal” session at the [MyData 2018 Conference](#).
- 2018 Panelist, “Changing Our Relationship to Algorithms in Our Lives and Our Research” at the Sage Bionetworks 2018 Assembly.
- 2017 Keynote, “Open Sourcing Ourselves” and “Open Data” session panelist at the [18th Annual Bioinformatics Open Source Conference](#).
- 2017 Panelist, “Tools, Resources, and Communities” session at the Third Annual Health Data Exploration Network Meeting: “Promoting Social Justice in the Use of Personal Health Data”.
- 2017 Speaker, “Uncomfortable Data” session at “Our World, Our Data: Taking Collective Responsibility for Citizen and Environmental Sensing”.
- 2017 Speaker, “Participant Reflections” session & Young Investigator/Innovator Award (jointly with Dana Lewis): “OpenAPS Commons: A citizen-driven data commons enabled by the Open Humans system”, [Sage Bionetworks 2017 Assembly](#).
- 2016 Panelist, “A Public Infrastructure for Data Access” at the [Quantified Self Public Health Symposium](#).
- 2016 Presenter, “Enabling Personal Health Data Donation: Models that Work” session at the [Health Data Exploration Project Network Meeting](#).
- 2015 Panelist, “Picked Out of a Crowd: Privacy and Re-Identification Research” at PRIM@R’s [Advancing Ethical Research Conference](#).
- 2015 Presenter, “Opening Up Access” at the [Quantified Self Public Health Symposium](#). (On Vimeo.)

Selected publications

- 2019 [Predispositional genome sequencing in healthy adults: design, participant characteristics, and early outcomes of the PeopleSeq Consortium](#). Zoltick ES, Linderman MD, McGinniss MA, Ramos E, Ball MP, Church GM, Leonard DGB, Pereira S, McGuire AL, Caskey CT, Sanderson SC, Schadt EE, Nielsen DE, Crawford SD, Green RC; PeopleSeq Consortium. *Genome Med*, Feb 27 2019.
- 2018 [User Perspectives of a Web-Based Data-Sharing Platform \(Open Humans\) on Ethical Oversight in Participant-Led Research: Protocol for a Quantitative Study](#). Fadda M, Jobin A, Blasimme A, Greshake Tzovaras B, Price Ball M, Vayena E. *JMIR Res Protoc*, Nov 28 2018.
- 2018 [Exploring Genetic Data Across Individuals: Design and Evaluation of a Novel Comparative Report Tool](#). Westendorf L, Shaer O, Pollalis C, Verish C, Nov O, Ball MP. *JMIR Res Protoc*, Sep 24 2018.
- 2016 [The whole genome sequences and experimentally phased haplotypes of over 100 personal genomes](#). Mao Q, Ciotlos S, Zhang RY, Ball MP, Chin R, Carnevali P, Barua N, Nguyen S, Agarwal MR, Clegg T, Connelly A, Van-

dewege W, Zaranek AW, Estep PW, Church GM, Drmanac R, Peters BA. *Gigascience*, Oct 11 2016.

2016

[Social Annotation Valence: The Impact on Online Informed Consent Beliefs and Behavior.](#)

Balestra M, Shaer O, Okerlund J, Westendorf L, Ball M, Nov O. *J Med Internet Res*, July 2016.

2016

[GenomiX: A Novel Interaction Tool for Self-Exploration of Personal Genomic Data.](#)

Shaer O, Nov O, Okerlund J, Balestra M, Stowell E, Westendorf L, Pollalis C, Westort L, Davis J, Ball M. *Proc. CHI 2016 Computer-Human Interaction*, May 2016.

2015

[Personal Data Freedom.](#) Madeleine Ball. *Quantified Self: Access Matters*, Feb 11 2015.

2014

[Harvard Personal Genome Project: lessons from participatory public research.](#)

Ball MP, Bobe J, Chou MF, Clegg T, Estep PW, Lunshof JE, Vandewege W, Zaranek A, Church GM. *Genome Med*, Feb 28 2014.

2013

[Our genomes today: time to be clear.](#) Jeantine Lunshof & Madeleine Ball. *Genome Med*, Jun 27 2013.

2012

[A public resource facilitating clinical use of genomes.](#)

Ball MP, Thakuria JV, Zaranek AW, Clegg T, Rosenbaum AM, Wu X, Angrist M, Bhak J, Bobe J, Callow MJ, Cano C, Chou MF, Chung WK, Douglas SM, Estep PW, Gore A, Hulick P, Labarga A, Lee JH, Lunshof JE, Kim BC, Kim JI, Li Z, Murray MF, Nilsen GB, Peters BA, Raman AM, Rienhoff HY, Robasky K, Wheeler MT, Vandewege W, Vorhaus DB, Yang JL, Yang L, Aach J, Ashley EA, Drmanac R, Kim SJ, Li JB, Peshkin L, Seidman CE, Seo JS, Zhang K, Rehm HL, Church GM. *Proc Natl Acad Sci U S A.*, July 24 2012.

Technical skills

PROGRAMMING LANGUAGES

- Python
 - Web frameworks (Django & Flask)
 - REST API and OAuth2 (django-rest-framework & django-oauth-toolkit)
 - Module management, development, and deployment (pipenv, PyPI)
 - Asynchronous processing (Celery)
 - Scientific data processing (biopython, jupyter, numpy, pandas, scipy)
- JavaScript
 - AJAX and front-end development (jQuery)

MARKUP LANGUAGES & SERIALIZATION FORMATS

- CSS/SCSS, HTML, JSON, Markdown, XML

CLOUD SERVICES

- DevOps: AWS (EC2, S3, Route 53), Codeship, GitHub, Heroku, Sentry
- Organization operations & communications (G Suite, Desk.com, Mailchimp, Slack)