



Ilaria Galasso, Post Doctoral Researcher  
 Iliaria.galasso@ucd.ie @ilagalasso

## BACKGROUND

- **Contemporary medicine is essentially data-driven:** genomic medicine, precision medicine, personalized medicine, and even classical epidemiology, are grounded on personal data collection and comparison, which contemporary technologies facilitate at very massive and at the same time detailed scales.
- **Data-driven medicine relies on inclusive and diverse public participation in data-sharing programs** (Epstein 2007): In order to reach statistical significance and wide applicability, medical datasets are required to be as large and diverse as possible (Cohn et al. 2017).
- **Concerns around data control generate defection:** data ownership, control and rights are often ambiguous concepts; these ambiguities may generate discontent. While in other contexts discontent triggers mobilization and negotiation, in data-sharing programs it disincentivizes participation, by perpetuating underrepresentation of some groups (Cohn et al. 2015).
- **A ‘participatory turn’ to enhance participation** (Prainsack 2017): several contemporary data-driven programs are committed to stimulating and encouraging participation by embracing a citizen science rhetoric (Woolley et al. 2016) to involve “participants as partners”.

## RESEARCH QUESTIONS

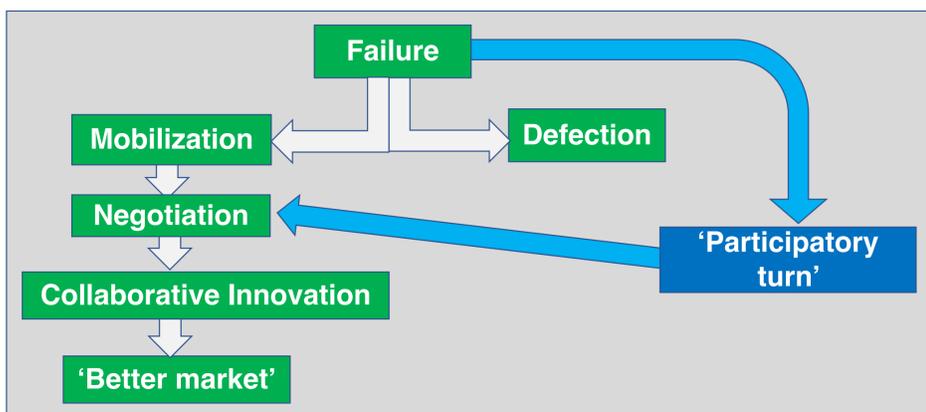
- 1) **How do publics react to perceived lack of control** on their own health-related data?
- 2) **To what extent could collaborative decision-making encourage health-related data-sharing.**
- 3) **Which formats** of (potential) participants involvement are **inclusive and effective** (Galasso and Testa 2017), as opposed to mere tokenism (Arnestein 1969, Kelty et al. 2015)

## AIMS AND OBJECTIVES

EPISTEMIC GOALS: to establish

- **in which cases failures around data-intensive healthcare research generates public mobilization,**
- **in which cases and in which formats collaborative decision-making could underpin democratic negotiation** and lead to **‘better markets’** by including the interests of vulnerable or historically underrepresented groups.

PRACTICAL GOALS: to engage with data-driven health-related initiatives to **promote the most efficient collaborative formats** for the pursuit of the equitable advancement of medicine.



## INDICATIVE CASE STUDIES

### a) National Research Cohorts and Lifesciences Companies:

- All of Us Research Program (US)
- 100,000 Genomes Program (UK)
- Genomics Medicine Ireland (Ireland)
- Personal Genomes Project (US, Canada, UK, Austria, China)

### b) Consumer Generic Testing Companies:

- 23andMe
- AncestryDNA
- Helix
- LunaDNA

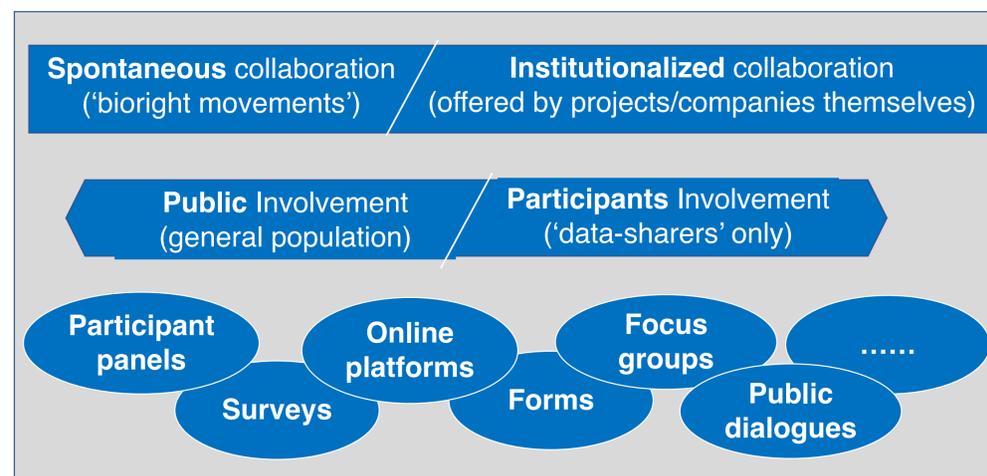
### c) Famous cases of concerned actors’ mobilization for data control (‘biorights activism’):

- Henrietta Lacks’ case (cell line harvested and used with no consent nor knowledge)
- SharDna and Identità Ogliastrina case (genetic data sold to a foreign company with no re-consent)
- Havasupai Tribe case (genetic data used beyond consent)

## RESEARCH DESIGN

**Comparative analysis** (through document analysis, initiatives monitoring, interviews and direct participation) of collaborative decision-making procedures in terms of:

- Inclusiveness
- Effectiveness
- Facilitation of ‘inclusive and diverse’ data sharing



## REFERENCES

- Arnstein S. (1969), A ladder of citizen participation, *Journal of the American Planning Association*, 35:4, 216-24
- Cohn E. G. et al. (2015), Increasing Participation in Genomic Research and Biobanking Through Community-Based Capacity Building, *J Genetic Counsel*, 24, 491-502.
- Cohn E. G., et al. (2017), Distributive justice, diversity, and inclusion in precision medicine: what will success look like? *Genetics in Medicine*, 19:2, 157-59.
- Epstein S. (2007), *Inclusion: The Politics of Difference in Medical Research*, University of Chicago Press.
- Galasso I. and Testa G. (2017), Citizen Science and Precision Medicine: A Route to Democracy in Health? on *Harvard Law / Petrie Flom Center Bill of Health Blog*
- Kelty C. et al. (2015), Seven Dimensions of Contemporary Participation Disentangled, *Journal of the Association for Information Science and Technology*, 66:3, 474-88.
- Prainsack B. (2017), *Personalized Medicine: Empowered Patients in the 21st Century?*, New York University Press.
- Woolley J. P. et al. (2016), Citizen science or scientific citizenship? Disentangling the uses of public engagement rhetoric in national research initiatives, *BMC Medical Ethics*.

© MISFIRES - UCD, 2019