

COMMENTARY

Bermuda 2.0: reflections from Santa Cruz

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Abstract

In February 1996, the genome community met in Bermuda to formulate principles for circulating genomic data. Although it is now 20 years since the Bermuda Principles were formulated, they continue to play a central role in shaping genomic and data-sharing practices. However, since 1996, “openness” has become an increasingly complex issue. This commentary seeks to articulate three core challenges data-sharing faces today.

Key words: Data; Sharing; Bermuda Principles; Openness

Background

In February 1996, leaders in genome science convened in Bermuda and penned principles for circulating genomic data that endure today [1]. The story of the Bermuda Principles and the commitment to daily sharing of DNA sequences prior to publication has become one of the dominant narratives of the

Human Genome Project (HGP). Motivated in part by an attempt to keep the human genome sequence in the public domain, the Bermuda Principles inaugurated a commitment to openness at the heart of the new field of genomics [Fig 1]. Since 1996, however, the issues surrounding “openness” have become increasingly complex, raising new questions about the meaning

Received: 7 November 2016

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Three Bermuda Meetings

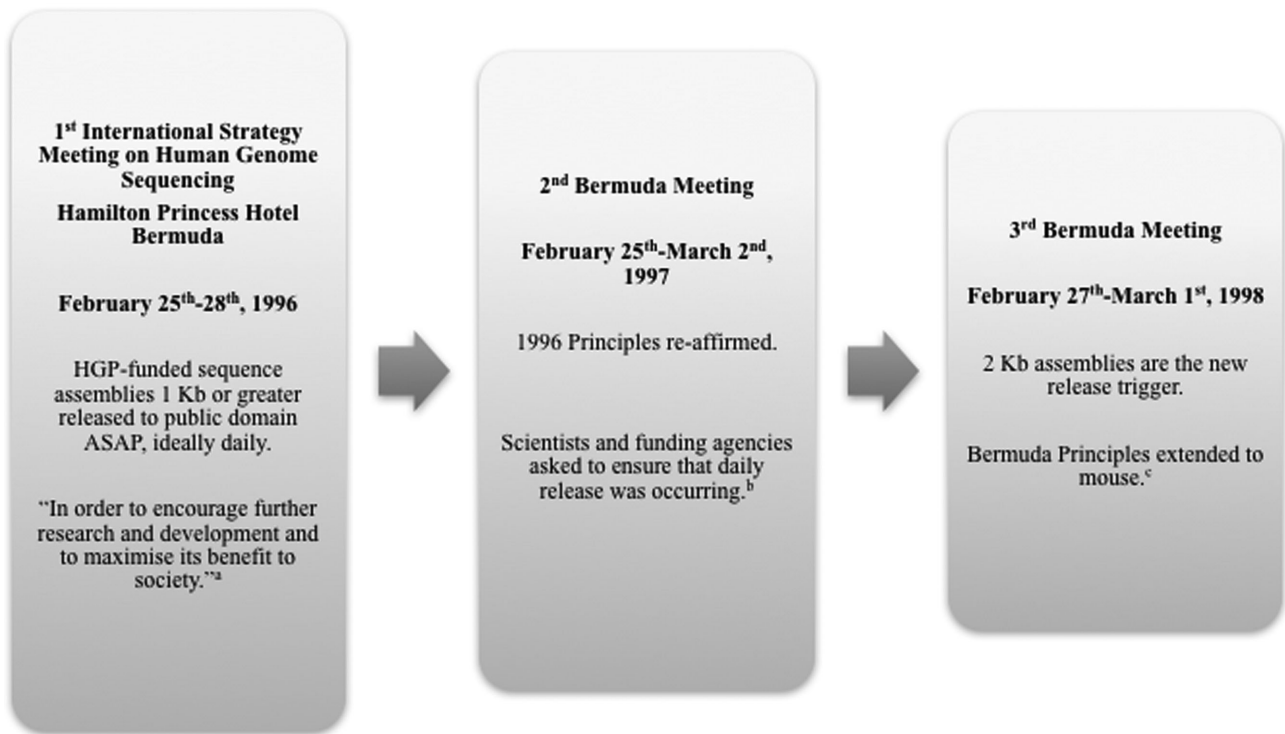


Fig. 1 Three "Bermuda Meetings" were held in 1996^a, 1997^b, and 1998^c. At each subsequent meeting the principles for data sharing were affirmed, extended, updated, and refined.

of openness itself, and how and why it should be enacted and enforced.

Two decades after the meeting in Bermuda, on November 18, 2015, some original members of the Bermuda meetings, along with other genome scientists and social scientists, gathered at University of California Santa Cruz to reflect on what 'open genomics' means in the context of the post-HGP conditions: the exponential growth of genomic data, the centrality of private funding, and commitment to the right of privacy [2]. The hypothesis at Santa Cruz was that revisiting the historic Bermuda Principles would clarify what is at stake in today's decisions about how and whether to share data, with whom, and on what platforms. The participants articulated three core challenges that suggest ways to frame the ethical, political, and technical dilemmas that lie ahead.

Challenge one: what is data?

In 1996, the 'data' that occupied participants' attention were the nucleotide sequences needed to create a single human reference sequence. Today, however, the forms of relevant data are proliferating, creating new puzzles for clinicians, genome scientists, epidemiologists, and potential patients and research participants. We have expanded our capabilities from analyzing and interpreting one individual's data to exponential numbers of people and exponential amounts of data. These derive not just from sequences, but also from other 'omics' data, such as metabolomics, metagenomics, proteomics, epigenomics and exposomics, which is now increasingly linked to socio-economic, behavioral, genealogical, clinical, and GIS data. Despite manifest

differences between different types of data, the Bermuda Principles are often invoked as a touchstone for the "right" approach to use and reuse.

However, the uses and value of these data - and proper structures for their governance - are often far from clear. Practitioners within different subfields collect, process, clean, report, and analyze data in different ways. What counts as data thus often depends on specific disciplinary norms, standards, and modes of valuation. Data collected via automated, high-throughput techniques may be valued differently by experimenters, publishers and regulators than curated data or data coded through long-term fieldwork.

Furthermore, practices for creating valuable data in small communities often differ from those in very large ones. Before and during the early phases of the HGP, model organism communities (in particular, those studying *Caenorhabditis elegans* and *Drosophila*) developed varied norms and practices for collecting, curating, and communicating data. At Santa Cruz, Jenny Bangham, Robert Kuhn, and Bob Waterston discussed some early tools used for sharing information and assigning credit, such as the newsletters *Drosophila* Information Service and *The Worm Breeder's Gazette* [3]. Even in such close-knit communities, pre-publication 'sharing' occurred within carefully managed networks and systems of trust and credit [Fig. 2].

Today genomic data are no longer created solely within the confines of model organism communities. Rather, data are often donated by individuals with interests in how they are used. How then do scientists make decisions about data's value when there is no community to ensure quality control (e.g., for species that are not model organisms)? Without the guidance of community

healthcare systems, data governance cannot ignore the fact that today's -omic data are collected and used within inequitable and fragmented healthcare infrastructures, particularly in the US [9]. A policy of open data will not guarantee that everyone has equal access or benefits. We thus face the challenge of creating not just an open, but also a just approach to sharing biomedical data [10].

Toward 'Good' genomic science

The moral grounds that solidified during the HGP, complex as they were, no longer provide adequate guidance. At Santa Cruz, we updated the received views about the Bermuda Meetings, transforming the principles of 1996 into key challenges for 2016 and beyond. The Santa Cruz challenges show us that we need a better understanding of the actual practices and stakes involved in data sharing. We must clarify what we mean when we talk about genomic data and "the public good." Understanding how value is created through specific flows of data will lay the groundwork for more engaged deliberations about the benefits and drawbacks of various sharing regimes. Developing robust agreements about data governance in the postgenomic era requires creating experimental spaces and cross-disciplinary dialogues such as those at Santa Cruz.

Abbreviations

HGP Human Genome Project.

Competing interests

The authors and collaborators have no competing interests to declare.

Funding

Financial support for the Genomic Open workshop was provided by the Science and Justice Research Center and the UC Santa Cruz Genomics Institute.

Authors' contributions

JR led the writing of this essay and drafted the first draft with KD. HS, SH, and JR led the drafting of the shortened version. All authors contributed to the writing of the final version. JB, KMJ and HS created the infographics.

Acknowledgements

The authors would like to acknowledge the staff of the Science and Justice Research Center for support of the Genomic Open workshop and early efforts to formulate this commentary, in particular Colleen Massengale and Emily Cohen Ibañez. We would also like to acknowledge the very helpful critical feedback provided by Julie Harris-Wai, David Haussler, Bob Waterston on earlier versions of this essay.

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Endnotes

A) The 1996 Bermuda Meeting Report can be found at <http://hdl.handle.net/10161/7715>, B) The 1997 Bermuda Meeting Report can be found at <http://hdl.handle.net/10161/7733> and C) The 1998 Bermuda Report can be found at <http://hdl.handle.net/10161/7745>.

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