Open and Responsible Data Governance for Digital Sequence Information: Policy Paper in View of the Ongoing Process under the Convention for Biological Diversity to Establish a Benefit-Sharing Mechanism for Digital Sequence Information

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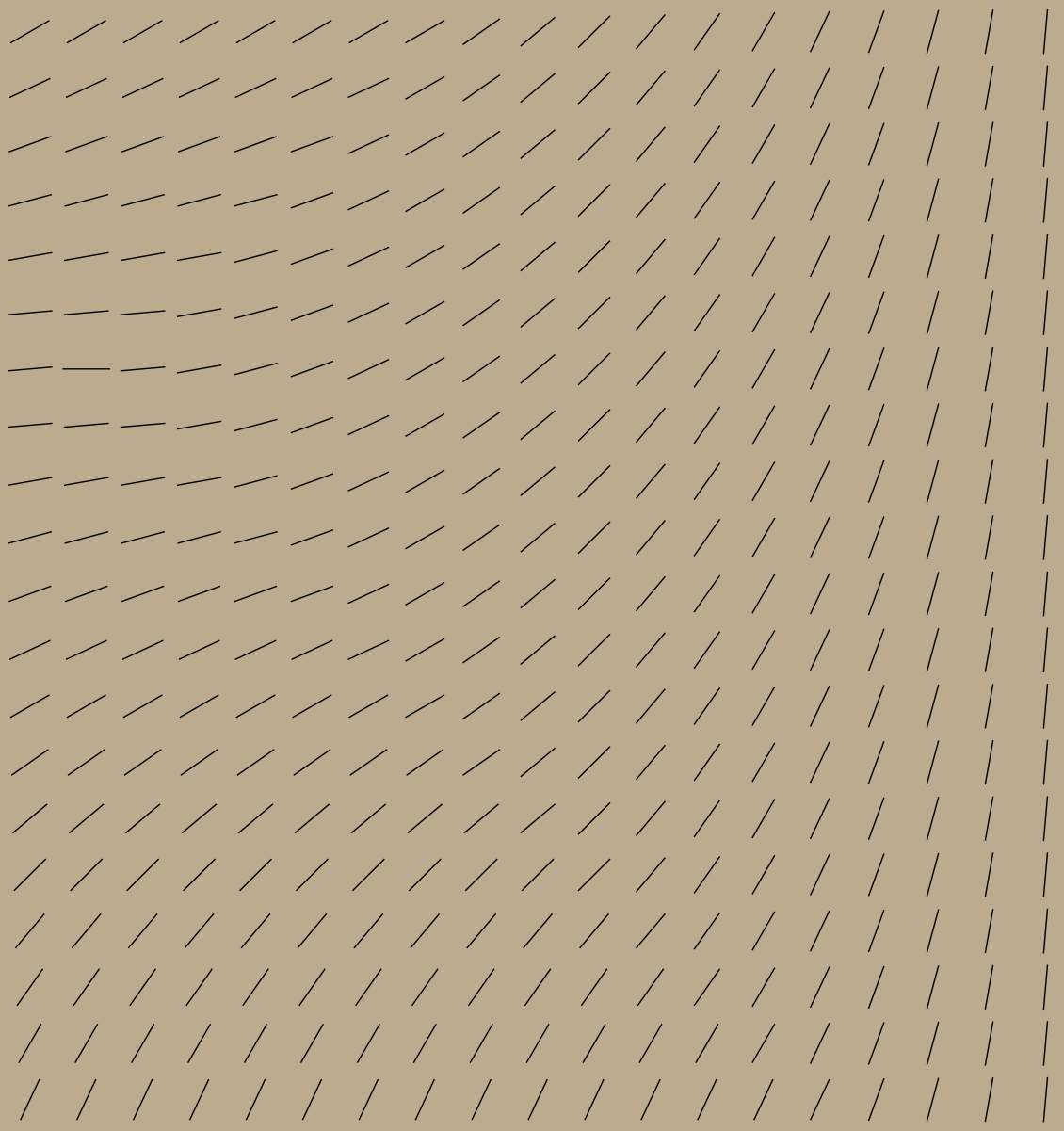

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The Weizenbaum Institute – The German Internet Institute analyzes, evaluates and shapes relevant aspects of the digitally networked society. With basic, interdisciplinary and problem-oriented research projects on the ethical, legal, economic, political and social dimensions of digital change and the exploration of concrete solutions, it provides politicians, business and civil society with evidence- and value-based options for action in order to shape digitalization in a sustainable, self-determined and responsible manner. The Institute is supported by a research network from Berlin and Brandenburg, which includes Freie Universität Berlin, Humboldt-Universität zu Berlin, Technische Universität Berlin, Berlin University of the Arts, and the University of Potsdam, as well as the Fraunhofer Institute for Open Communication Systems (FOKUS) and the WZB Berlin Social Science Center. The Weizenbaum Institute is funded by the German Federal Ministry of Education and Research (BMBF) and the State of Berlin. For more information, visit: www.weizenbaum-institut.de.

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I. Introduction

Access and benefit-sharing is a mechanism established by the Convention for Biological Diversity (CBD) in 1992 to share fairly and equitably the benefits arising from the utilization of genetic resources and to contribute to the conservation of biodiversity.[1] Benefit-sharing can thus play an important part in the transformative change[2] and considerable financial resources[3] required in the race against the mass extinction of species we are currently facing. However, since the signing of the CBD in 1992 the biotechnological landscape has changed drastically. Today, genetic information from genetic resources can be obtained rapidly and at a low cost through, inter alia, DNA sequencing. The data obtained is of vital importance for fundamental research and industry, for example, and most importantly recently, the development of vaccines.

Whether the benefits arising from the utilization of such data need to be shared like from genetic resources has been heavily disputed between the Parties to the CBD. The Conference of the Parties addressed this question in 2016 and established digital sequence information (DSI) as the placeholder term for information and data obtained from genetic resources.[4] Just like the negotiations of the CBD, DSI is a highly political topic with many ethical, legal, social and economic dimensions, including questions of fairness and equitability between the global south and north, the rights of Indigenous Peoples as stewards of biodiversity, and resource mobilization for the conservation of biodiversity. Therefore, the decision[5] at the 15th Conference of the Parties (COP15) in Montreal in December 2022 to establish a mechanism for benefit-sharing from the use of DSI was groundbreaking. However, the design and data governance of such a mechanism will be crucial in

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1 This policy paper is based on a submission made by the Weizenbaum Institute to the Secretariat of the Convention on Biological Diversity regarding issues for further consideration for digital sequence information on genetic resources, see https://www.cbd.int/doc/notifications/2023/ntf-2023-003-abs-dsi-en.pdf (last visited Mar 28, 2023). The policy paper reproduces the main part of the submission, but an introduction and some additional references have been added to provide some background information for those not familiar with the policy process.

2 See IPBES, *Global assessment report on biodiversity and ecosystem services of the Intergovernmental Science-Policy Platform on Biodiversity and Ecosystem Services*, (2019), https://zenodo.org/record/6417333 (last visited Mar 28, 2023).

3 ANDREW DEUTZ ET AL., *Financing Nature: Closing the global biodiversity financing gap (Foreword and Executive Summary)*, (2020), https://www.paulsoninstitute.org/wp-content/uploads/2020/10/Updated-10.23.20-FINANCING-NATURE_Exec.-Summary_Final-with-endorsements_101420.pdf (last visited Mar 28, 2023).

4 Conference of the Parties to the Convention on Biological Diversity, *Decision XIII/16, Digital sequence information on genetic resources*, (2016), https://www.cbd.int/doc/decisions/cop-13/cop-13-dec-16-en.pdf (last visited Mar 28, 2023).

5 Conference of the Parties to the Convention on Biological Diversity, *Decision 15/9, Digital sequence information on genetic resources*, (2022), https://www.cbd.int/doc/decisions/cop-15/cop-15-dec-09-en.pdf (last visited Mar 28, 2023).

achieving fair and equitable benefit-sharing and contributing to the conservation of biodiversity.

II. Open and Responsible Data Governance

The Weizenbaum Institute welcomes the acknowledgement of the FAIR and CARE principles in Decision 15/9. However, further work is required for a more granular understanding of the principles' implications for DSI-specific data governance. The Weizenbaum Institute supports Open and Responsible Data Governance as a means to integrate the FAIR and CARE principles in the design of a multilateral benefit-sharing mechanism. The term "Open and Responsible Data Governance" has only recently been developed at COP15 by, inter alia, the International Indigenous Forum on Biodiversity (IIFB) and an interdisciplinary research group on DSI (iDSI).[6] Therefore, Open and Responsible Data Governance requires further development and clarification. However, Open and Responsible Data Governance is a promising concept to develop a DSI-tailored understanding of the FAIR and CARE principles, their possible tensions, and implications for a fair and equitable DSI benefit-sharing mechanism.

III. The FAIR Principles

The FAIR principles[7] inform on how data governance can enable generating benefits from the use of DSI and how open data and Fair principles translate into criteria which can be used for assessing DSI policy options for a multilateral mechanism.[8] In particular, open data and FAIR principles point towards a multilateral benefit-sharing mechanism for DSI which:

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[6] See Paul Oldham, Claudio Chiarolla & Siva Thambisetty, *Digital Sequence Information in the UN High Seas Treaty: Insights from the Global Biodiversity Framework-related Decisions*, 5 (2023), https://papers.ssrn.com/abstract=4343130 (last visited Mar 28, 2023).

[7] See Mark D. Wilkinson et al., *The FAIR Guiding Principles for scientific data management and stewardship*, 3 SCI. DATA. 160018 (2016), http://www.nature.com/articles/sdata201618 (last visited Mar 28, 2023).

[8] Irma Klünker & Heiko Richter, *Digital Sequence Information between Benefit-Sharing and Open Data*, 9 J.L. & BIOSC. lsac035 (2022), https://academic.oup.com/jlb/article/9/2/lsac035/6840099 (last visited Mar 28, 2023).

- does not distinguish between commercial and non-commercial use of DSI upstream, but, if at all necessary, downstream to enable re-use of DSI and follow-on innovation which then generates monetary benefits[9]
- cautions against multiple standard licenses as these could disincentivize the use of DSI mandating benefit-sharing[10]

However, the FAIR principles do not come without restraints, but include the concept of "as open as possible, as closed as necessary".[11] This restraint opens a conceptual window to include principles of responsibility into DSI data governance as reflected in the concept of Open and Responsible Data Governance.

IV. The CARE principles

The CARE principles[12] inform on how a DSI benefit-sharing mechanism is not only open but how such a mechanism can be responsible by safeguarding and promoting indigenous data sovereignty.[13] One of the tensions between the FAIR and the CARE principles could be the trigger point of benefit-sharing. While the FAIR principles point towards decoupling access from benefit-sharing, e.g. through a levy,[14] it is essential that a DSI benefit-sharing mechanism enables Indigenous Peoples and local communities to control their data.[15] Further research and active participation of indigenous rights holders are required on the question of whether decoupling access from benefit-sharing would be consistent with the CARE principles and ensure Open and Responsible Data Governance.

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[9] *Id.* at 25.

[10] *Id.* at 26.

[11] In the context of DSI, "as open as possible, as closed as necessary" has been discussed by Jacob Golan et al., *Benefit sharing: Why inclusive provenance metadata matter*, 13 FRONT. GENET. 1014044, 3 (2022), https://www.frontiersin.org/articles/10.3389/fgene.2022.1014044 (last visited Mar 28, 2023); Klünker and Richter, *supra* note 8 at 19.

[12] See Stephanie Russo Carroll et al., *The CARE Principles for Indigenous Data Governance*, 19 DATA SCI. J. 43 (2020), http://datascience.codata.org/articles/10.5334/dsj-2020-043/ (last visited Mar 28, 2023).

[13] Ann M. Mc Cartney et al., *Balancing openness with Indigenous data sovereignty: An opportunity to leave no one behind in the journey to sequence all of life*, 119 PROC. NATL. ACAD. SCI. U.S.A. e2115860119 (2022), https://pnas.org/doi/full/10.1073/pnas.2115860119 (last visited Mar 28, 2023); Golan et al., *supra* note 11.

[14] Klünker and Richter, *supra* note 8 at 27. See also Amber Hartman Scholz et al., *Multilateral benefit-sharing from digital sequence information will support both science and biodiversity conservation*, 13 NAT. COMMUN. 1086, 3 (2022), https://www.nature.com/articles/s41467-022-28594-0 (last visited Mar 28, 2023).

[15] Mc Cartney et al., *supra* note 13 at 10.

V. Summary

Open and Responsible Data Governance is a promising concept to help operationalize the FAIR and CARE principles for DSI-specific data governance. While the CARE principles ensure indigenous data sovereignty is respected, the FAIR principles ensure that monetary benefits from the use of DSI are generated and form a part of resource mobilization for the conservation of biodiversity.