

SECONDARY DATA SHARING RESOURCES

NIH POLICY

1. **2023 NIH Data Management and Sharing Policy**
 - a. Overview of 2023 NIH Data Management and Sharing Policy
<https://sharing.nih.gov/data-management-and-sharing-policy/about-data-management-sharing-policy/data-management-and-sharing-policy-overview>
 - b. Text of 2023 NIH Data Management and Sharing Policy
<https://grants.nih.gov/grants/guide/notice-files/NOT-OD-21-013.html>
 - c. FAQs of 2023 NIH Data Management and Sharing Policy
<https://sharing.nih.gov/faqs#/data-management-and-sharing-policy.htm>

2. **2003 NIH Data Sharing Policy**
 - a. Overview of 2003 Data Sharing Policy
<https://sharing.nih.gov/data-management-and-sharing-policy/about-data-management-and-sharing-policies/data-management-and-sharing-policy-overview#before>
 - b. Final NIH Statement on Sharing Research Data, February 26, 2003
<https://grants.nih.gov/grants/guide/notice-files/NOT-OD-03-032.html>
 - c. FAQs of 2003 NIH Data Sharing Policy
<https://sharing.nih.gov/faqs#/data-sharing.htm>

3. **Scientific Data Sharing**

NIH Office of Science Policy Scientific Data Sharing Policy Division
<https://osp.od.nih.gov/policies/scientific-data-management-policy/>

4. **Research Program Data and Resource Management and Sharing Plans**

NCI Division of Cancer Control and Population Sciences Epidemiology and Genomics
<https://epi.grants.cancer.gov/funding/resource-data-sharing-plan.html>

NIH DATA SHARING PRESENTATIONS/RESOURCES

1. **NIH Scientific Data Sharing News and Events** (includes links to future and previous presentations, news, and resources)
<https://sharing.nih.gov/news-events>

2. **NIH Scientific Data Sharing** <https://sharing.nih.gov/about/learning>
 - a. **Webinar I: Understanding the New NIH Data Management and Sharing (DMS) Policy** August 11, 2022
 - b. **Webinar II: Diving Deeper into the new NIH Data Management and Sharing Policy** September 22, 2022

3. **NCI Data Sharing: Broad and Equitable Access to Research**, Dr. Guidry Auvil Data Sharing webinar from May 20, 2019
<https://deainfo.nci.nih.gov/advisory/ncra/0519/NCI%20Office%20of%20Data%20Sharing%20-%20Dr.%20Guidry%20Auvil.pdf>
4. **NCI Center for Biomedical Informatics & Information Technology: Your Guide to the 2023 NIH Data Management and Sharing Policy**
<https://datascience.cancer.gov/news-events/blog/your-guide-2023-nih-data-management-and-sharing-policy>
5. **NIH Scientific Data Sharing Writing a Data Management and Sharing Plan** (including sample plans)
<https://sharing.nih.gov/data-management-and-sharing-policy/planning-and-budgeting-for-data-management-and-sharing/writing-a-data-management-and-sharing-plan#sample-plans>
6. **New Grantee Workshop 2019 NIH Data Sharing** NCI Division of Cancer Control and Population Sciences Division of Cancer Prevention Charlisce Caga-anan JD DCCPS Genomic Program Administrator (GPA) November 21, 2019
<https://cancercontrol.cancer.gov/sites/default/files/2020-08/2019-Data-Sharing.pdf>
7. **NIH Data Sharing and DbGaP** Charlisce Caga-anan JD MA October 14, 2022
<https://www.naacr.org/vpr-fact-sheets/>

NAACCR-FACILITATED RESOURCES

1. **Secondary Release of Cancer Registry Data**, NAACCR Webinar May 26, 2021, including **NIH Policies on Data and Resource Sharing** presented by Nonye Harvey, DrPH, Health Science Policy Analyst, National Institute of Health and Julia Slutsman, PhD, Director Genomic Data Sharing Implementation, National Institute of Health
<https://education.naacr.org/products/secondary-release-of-cancer-registry-data>
2. **VPR Fact Sheets and Resources** <https://www.naacr.org/vpr-fact-sheets/>
3. **Secondary Data Sharing Fact Sheet** https://www.naacr.org/wp-content/uploads/2023/02/Cancer-Registry-Secondary-Data-Sharing-Fact-Sheet_Final_2.9.23.pdf
4. **Editorial: Data Sharing for the Common Good: An Ethical Obligation?** Patrick Hill, PhD
https://www.ncra-usa.org/Portals/68/Journal%20of%20Registry%20Management/NCRA%20Summer%202022_v4_links4.pdf
5. **Virtual Pooled Registry Templated Data Use Agreement**
<https://www.naacr.org/vpr-fact-sheets/>

REFERENCES

1. Meyer MN. **Practical Tips for Ethical Data Sharing.** *Advances in Methods and Practices in Psychological Science.* 2018;1(1):131-144.
<https://journals.sagepub.com/doi/10.1177/2515245917747656>
2. Seastedt KP, Schwab P, O'Brien Z, Wakida E, Herrera K, Marcelo PGF, Agha-Mir-Salim L, Frigola XB, Ndulue EB, Marcelo A, Celi LA. **Global healthcare fairness: We should be sharing more, not less, data.** *PLOS Digit Health.* 2022;10(1).
<https://journals.plos.org/digitalhealth/article?id=10.1371/journal.pdig.0000102>
3. Mello MM, Lieou V, Goodman SN. **Clinical Trial Participants' Views of the Risks and Benefits of Data Sharing.** *N Engl J Med.* 2018;378(23):2202-2211.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6057615/>
4. Bentzen HB, Castro R, Fears R. *et al.* **Remove obstacles to sharing health data with researchers outside of the European Union.** *Nat Med.* 2021;27: 1329–1333.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6057615/>