



ELSI

Updated 04/12/2023

The ELSI (Ethical, Legal, and Social Issues) Committee moderates discussion of matters regarding access to and use of TOPMed data. The Committee has considered consent, participant privacy, and implementation issues regarding: (1) public sharing of variant summary data in the TOPMed variant server (BRAVO, see URLs); (2) public access to use of a TOPMed reference panel in a genotype imputation server (without sharing individual-level data); (3) sharing detailed information about variants of interest with outside investigators for follow-up studies; and (4) return of results to study participants. Summary reports prepared by the Committee contain points for study investigators to consider in making decisions about each issue. These reports are provided below, listed by topic and date:

1. [Return of genetic results to TOPMed participants](#) [1] (January 2016)
2. [TOPMed BRAVO variant server](#) [2] (August 2016)
3. [TOPMed imputation reference panel](#) [3] (September 2016)
4. [Stratified allele frequencies](#) [4] (April 2021)

Source URL (modified on 04/12/2023 - 3:38pm):<https://topmed.nhlbi.nih.gov/elsi>

Links

[1] https://topmed.nhlbi.nih.gov/sites/default/files/TOPMed.ELSI.recommendations_1.v6.pdf [2]

https://topmed.nhlbi.nih.gov/sites/default/files/ELSI.BRAVO.v2_7Aug2016.pdf [3]

<https://topmed.nhlbi.nih.gov/sites/default/files/ELSI%20Review%20of%20TOPMed%20Imputation%20Server.pdf>

[4] <https://topmed.nhlbi.nih.gov/sites/default/files/TOPMed-ELSI-stratified-freqs-pts-to-consider.pdf>