

California Biobank Program Security & Confidentiality Practices

The aim of the California Department of Public Health's (CDPH) California Biobank Program (CBP) is to avoid any impact on individuals' privacy while continuing to pursue the important public health efforts of the Department. The California Biobank Program consists of an assortment of personal and medical information collected from mothers and their babies born in California. All personal and medical information collected are stored securely and are strictly confidential. Safeguards include protected computer networks, encrypted data, secured facilities and laws that emphasize strict confidentiality. Since the conception of this program, there has never been any instance of a privacy breach.

The CBP takes these confidentiality requirements extremely seriously and there are severe penalties for the unlawful release of any information that identifies a parent or infant. Protecting privacy is a fundamental aspect of maintaining the integrity of the CBP. Securing the confidence of parents ensures that the CBP can maintain a robust collection of samples and data that may be used:

1. repeat a test without requiring a new sample be taken,
2. improve current testing methods and maintain quality assurance,
3. to develop tests for new disorders,
4. complete future testing for the individual if needed,
5. or for important health related research studies.

All specimens or data provided to researchers must be kept secure and must either be returned to the Department or destroyed at the conclusion of either further testing or research studies. Specimens or data that contain identifying personal information are never released to researchers or outside agencies without prior approval of the parents or individual. In addition, any study requesting to utilize the CBP's confidential information must have prior approval from the [State Committee for the Protection of Human Subjects](#). This committee reviews all research involving the use of individuals' private information to ensure it is used fairly and ethically.

The availability of a broad range of specimens and data in the CBP allows the Department to develop new testing methods and advance research into diseases effecting women's and children's health, that may improve and benefit the health outcomes of babies and their families not only in California but globally.

For further information regarding CBP security and confidentiality practices, please review our governing statutes and regulations at: [CBP Statutes and Regulations](#) or contact the California Biobank Coordinator at (510) 412-1500 or at BiobankProgram@cdph.ca.gov.

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