

RGE and UPDB – Questions

1. What specific statutory authority do Utah Resource for Genetic and Epidemiologic Research (RGE) and Utah Population Database (UPDB) have to collect, store and use the highly sensitive medical, driver license, voter registration, genealogical, birth and multiple other records of Utahns?
2. Which governmental and non-governmental entities provide data resources to the RGE and UPDB?
3. Would the administrators of the RGE and UPDB support requiring informed consent before using any personally identifiable information and personally identifiable medical information?
4. Would the executive branch support statutory changes requiring agencies of the government to provide informed consent before collecting any personally identifiable information and personally identifiable medical information, except in the commission of a crime? And a provision that, if the individual is later exonerated or charges are not filed, the PII and Medical PII must be destroyed?
5. Do entities holding Utahns' most sensitive individual identifying and medical information obtain the informed consent of the individual before transferring their records to the RGE and UPDB? If not, why not?
6. Do the RGE and UPDB obtain the informed consent of individuals before releasing their de-identified information for research, policy and other purposes? If not, why not?
7. Who decides when an individual's identifiable medical and other information will be released for research, policy, and other purposes? Who ensures that all individuals who are granted access to the UPDB are not copying, saving, or in any way storing any of the information in the database? Who ensures compliance with researcher agreements and how?
8. Why does the Utah Drivers License Division MOU with the RGE, dated 1-2-2018, include the following requirement: "Individuals contacted based on data contributed by DLD may not be informed contact was from data provided by the DLD?"
9. Do individuals whose data is being considered for release have an elected representative on the RGE Committees and/or on the Institutional Review Boards (IRB) that approve research proposals?

10. Given that data is the new currency, what property interests do Utahns have in their most sensitive medical and individual identifying information that the RGE and UPDB collects and distributes for research purposes?
11. When new billion-dollar products are developed that come from research conducted using Utahns' most sensitive medical and individual identifying information, what do these Utahns receive in terms of compensation? Free drugs, treatments, royalties, etc.?
12. How can individuals find out which records, and the specific information in those records, that the RGE and UPDB have on them?
13. Should an entity other than the University of Utah be given statutory control over the RGE and UPDB and should IRBs have elected citizen representatives on them?
14. Do you have a defined plan for a data breach response at both the UPDB level and the individual researcher level? Has the plan ever been activated?
15. Are the datasets used by researchers de-identified to a level that prevents the researcher or UPDB staff from reconstructing the original data subject's identity?
16. Are researchers allowed to take data obtained from UPDB and aggregate it into AI training models?
17. What contractual relationship exists between UPDB and researchers to ensure that data obtained from the UPDB is deleted at the conclusion of a study?
18. What is the process for handling reports of privacy violations and misuse of data?
19. Are any identifiable student records held by the RGE or the UPDB?
20. Is there anything else you would like to share with us?