

EPV ResearchKit Privacy Statement

Effective Date: Friday, February 5, 2016

The EPV (Estimated Placental Volume) ResearchKit app does not transmit personal information (name, iPhone telephone number, email or physical address) to the researchers at Yale University at anytime during its use. When a user first uses the app we assign them a 36 character random alpha numeric string representing their user ID. This is an example of such an ID: 9dc9a109-6b94-43ad-ff40-49659505ce7a. We then build a profile for that user from data they supply, which includes date of birth, and the mother's height and weight, as well as the iPhone supplied latitude and longitude.

When the patient enters their first and last name, and then signs the consent form, their name and signature are kept on the iPhone. A pdf form is created that is accessible only to the user of the iPhone. The signed consent and the patient's name are not shared with the server, nor sent to anyone by the EPV app. The signed consent pdf is created for the patient's reference and records. The patient can, if they wish, send their signed consent to themselves via their iPhone email, or print it from their iPhone, if they have access to an AirPrint equipped printer.

Data is sent from the EPV app to the EPV server using a secure HTTPs connection using Transport Layer Security (TLS 1.2) to encrypt all traffic (see https://en.wikipedia.org/wiki/Transport_Layer_Security for details).

Throughout the pregnancy, as the patient enters additional data the server receives updates which include the EPV measurements (width, height, thickness, EPV), the time (weeks/days) since the pregnancy began, and the mother's blood pressure.

When the baby is delivered, we ask the patient to supply some additional information on the pregnancy outcome. This includes:

The baby's gender

The delivery date

The APGAR scores at 1 and 5 minutes

The outcome of the pregnancy from a multiple choice list of five options.

The data sent from the EPV app is stored in an Amazon AWS data center (Northern Virginia) in a MySQL database. All data is stored in an encrypted volume in Amazon's data center. Encryption keys are managed using Amazon's key management system. This means that we are all protected against an Amazon employee physically stealing the hard drive in the data center. For more information on Amazon encrypted volumes (hard drives) see: <http://docs.aws.amazon.com/AWSEC2/latest/UserGuide/EBSEncryption.html>

The web server has no method for retrieving data. The iPhone EPV app has no ability to retrieve data from the server. Data can only be retrieved by logging into the server using a secure, encrypted SSH connection. Only public/private key based authentication is allowed (no password authentication). The SSH private key is a 2048 bit RSA key. Only Milad Fatenejad (the server engineer) and Harvey Kliman (the creator of the EPV method) have the server's SSH private key.

When Harvey Kliman accesses the server data, he only sees a table of results associated with an encrypted ID. There is no way to construct an identity from the data present on the Amazon EPV server. No EPV data collected will be shared with any other individuals. All the data will be used only by the researchers at Yale University to better understand the relationships between placental growth and volume, and pregnancy outcomes. Data will be held as long as the EPV ResearchKit study is ongoing.

For additional information about the Estimated Placenta Volume method, see:

<http://klimanlabs.yale.edu/placenta/epv/>

To contact Harvey Kliman, the Principle Investigator of this study, email him at:

[mailto:harvey.kliman@yale.edu?subject=EPV ResearchKit Study](mailto:harvey.kliman@yale.edu?subject=EPV%20ResearchKit%20Study).