



Data Collection Worksheet

Please Note: The Data Collection Worksheet (DCW) is a tool to aid integration of a PhenX protocol into a study. The PhenX DCW is not designed to be a data collection instrument. Investigators will need to decide the best way to collect data for the PhenX protocol in their study. Variables captured in the DCW, along with variable names and unique PhenX variable identifiers, are included in the PhenX Data Dictionary (DD) files.

The My Family Health Portrait (MFHP) is available at the following website:

<https://phgkb.cdc.gov/FHH/html/index.html>

The online tool includes questions about the individual followed by questions about each close family member. Once the required fields and health information are entered into the online tool, a pedigree containing all relevant information can be generated.

Important notes regarding the features and limitations of the MFHP:

- Although the MFHP can generate a pedigree, it does not store the information. But the information can be downloaded by the user and reloaded anytime for updates.
- Information from the MFHP is not meant to substitute for professional medical advice or care. Hence the MFHP does not provide personalized medical advice for an individual/their relatives for any condition or treatment.
- Users of the MFHP should consult a health care professional regarding medical advice/concerns/implications/questions due to their pedigree.
- The MFHP can be incorporated into an organization's suite of electronic information services without charge or royalty; however, an End User Agreement is required. If the MFHP is incorporated into an organization, customization is permitted; however, the standards-based features must be preserved. Details on the incorporation process are available by selecting the "Learn More About My Family Health Portrait" on the MFHP website.
- The MFHP is normally used for common diseases such as diabetes and cancer, so new diseases would need to be added. The user can add diseases in the "other" field of the form.

Protocol source: <https://www.phenxtoolkit.org/protocols/view/221001>