

Implementing Family Health History (FHH) Guidelines in Clinical Practice using Electronic Health Records (EHR)

Key Takeaways:

- 1. Why** Increasing collection and use of family health history (FHH) in your healthcare facility can improve health outcomes for your patients.
- 2. What** Use this resource to assess your healthcare facility's level of readiness, and as a guide to determine what is needed to progress to the next level.
- 3. How** This resource provides questions to guide the needs assessment for three levels of readiness to collect, to record, and to use family health history information in clinical practice: plan, implement, and evaluate.
- 4. Whom** This resource is meant for dissemination to healthcare facilities and State Departments of Health.

Levels of Readiness

This resource classifies levels of readiness as Mile 1 [Plan], Mile 2 [Implement], and Mile 3 [Evaluate], keeping in mind that healthcare facilities may identify themselves at more than one of these levels.

Assessment for Mile 1 (Plan)

Identify a Champion

- Do you have a champion within your facility who can lead this project?
- Is there a buy-in from leadership for this project?
- If not, is the champion willing to work with leadership to highlight the rationale and value of such a project?

Staffing Needs

- Do you know which teams/programs to contact within your facility to implement FHH in clinical practice?
- Is there a list of outside partners who are needed for this process?
- Do you know whom to contact within each team/program?

Resource Needs

- Is there an implementation plan in place with a reasonable timeline to implement?
- Are there resources (internal or external) that can be used to aid in the implementation of FHH in clinical practice?

Training Needs

- What are the training needs for such an implementation?
- Who will need to be trained and how will it be paid for?

At the end of Mile 1, your health care facility should have a plan in place for collecting, documenting, and using FHH.

Assessment for Mile 2 (Implement)

Data Policy Needs

- Is there a formal written policy in place asking for FHH to be documented?
- Is there a process currently in place to collect, update, and validate FHH records in the facility?

Data Collection Needs

- How are the data collected? Do patients input the data prior to appointment, do providers ask questions and clarify the answers to document a pedigree and the FHH for the immediate family?
- If there is no process in place – the champion will work with the relevant teams to create one.

Data Storage Needs

- Where will the FHH records be stored?
- Does the facility use EHR?
- If the facility does not use or have up-to-date EHR, what other options exist currently to store and use FHH in clinical decision-making?

Clinical Decision Support Needs

- Are there known gaps in FHH knowledge among providers that can be addressed with clinical decision support?
- Are there other tools and resources to aid patients in decision-making around FHH?
- Are there clear and concise best practice alerts around FHH that will not overload a provider?

Genetic Services Needs

- Are there processes in place for appropriate referrals to genetic counseling and other services based on risk assessment from FHH?
- Are there processes in place to return the results of risk assessment and genetic counseling/testing to patients and providers?

At the end of Mile 2, providers at your health care facility should be actively collecting, documenting, and using FHH.

Assessment for Mile 3 (Evaluate)

Record-Keeping Needs

- Is there adherence to therecord-keeping process? Do you have pilot data to evaluate adherence?
- If adherence is low, are there any QA/QI processes that can be put into effect to improve adherence?
- How up-to-date are the EHR records?

Evaluation Needs

- Is there a specific location where FHH are stored? Is it portable? Is it standardized across the facility?
- If not, are there any buildouts needed to make it portable and standardized?
- How often is a patient's FHH updated?
- How are they currently used?
- Are there best practice alerts that guide clinical decision making based on FHH in the EHR?
- Are there any procedures that can be automated or augmented using machine learning?
- Is there a role for curation of clinical data to aid in better understanding risk from FHH?
- Is there a plan for continued reassessment and future process improvement?

At the end of Mile 3, your health care facility should be evaluating whether your health care providers collect, document, and use FHH, and if this use aligns with current guidelines and best practices

A full implementation of FHH in clinical practice requires the clinic to have, and routinely collect, update, and validate patient records in such a tool, use it to guide clinical decisions, and evaluate use and documentation for alignment with current guidelines and best practices.

Is Family Health History (FHH) successfully incorporated as a decision-making tool routinely guiding patient care in your clinic?

- If the answer is no, do you want to implement FHH in clinical practice at your facility?
- If your facility has some implementation already in place, assess where you are on the Roadmap for Implementation Strategies. Here are some things to consider in your assessment.

(The domains listed above are not linear, i.e., it is possible for a facility to identify their current implementation practice model within different elements of each domain, but requiring more work to be done in each of the domains towards a successful implementation of FHH in their practice)

Family Health History FAQs

What is Family Health History (FHH) and why is it important?

Family health history is a record of the diseases and health conditions that run in families. Accurately collecting FHH and acting on it with the help of their provider can help an individual understand their risk of developing certain diseases and guide their health care decisions.

How is Family Health History (FHH) implemented in clinical practice?

Family health history is a valuable yet underused healthcare tool for assessing health risks for both prevalent disorders like diabetes, cancer, and cardiovascular diseases, and for rare, monogenic disorders. Full implementation of FHH collection and analysis in healthcare could improve both primary and secondary disease prevention for individuals and, through cascade testing, make at risk family members eligible for pre-symptomatic testing and preventative interventions. In addition to risk assessment in the clinic, FHH is increasingly important for interpreting clinical genetic testing results and for research connecting health risks to genomic variation. (Modernizing family health history: achievable strategies to reduce implementation gaps - PMC (nih.gov)).

Resources

- CDC Family Health History Homepage: <https://www.cdc.gov/genomics/famhistory/index.htm>
- Family Health History for Adults: <https://www.cdc.gov/family-health-history/adult/index.html>
- My Family Health Portrait- A tool from the Surgeon General: <https://cbiit.github.io/FHH/html/index.html>
- Family Health History for Patients and Families: genome.gov
- Collecting a Family History: <https://www.ama-assn.org/delivering-care/precision-medicine/collecting-family-history>
- Family Health History for Healthcare Professionals: <https://www.genome.gov/Health/Family-Health-History/Health-Professionals>

(Disclaimer this is a general guide to illuminate possible gaps. Any reference to "Patients" above includes patients themselves directly and/or their authorized caregiver)

This Road Map was created by the National Family Health History Working Group Subgroup 4: Implementation of Family Health History in Clinical Care and Public Health