# Health Heritage: A Decision Support Tool for the Collection and Assessment of Family Health History

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## Background

- Family health history (FHH) is the best way to assess risk for many common heritable diseases, including cancer.
- It is not currently being well documented or assessed.
- As a result: ~75% of people who need individualized screenings are not getting them.
- Plus: there is an ongoing debate related to over-screening and over-diagnosis – how are we to know who could postpone or reduce frequency of screening?

## Methods

1. **Clinical Validation** – Retrospective chart review of 55 randomly selected patients seen at an adult medical genetics clinic. The patients’ data were entered into HH, risk was assessed, and recommendations for genetic risk assessment (GRA) were compared to National Comprehensive Cancer Network (NCCN) recommendations for GRA.

2. **Clinician Feedback** - 5 focus groups with ~50 physicians and nurses to solicit feedback on the format and location for receiving HH results back into the EMR.

## Results

### High Risk Population

- 47 met NCCN criteria for Breast/Ovarian (Br/Ov) assessment.
- 1 met NCCN criteria for Lynch syndrome assessment.
- 1 met NCCN criteria for Polyposis syndrome assessment.
- 2 met criteria for Br/Ov and Lynch syndrome assessment.
- 4 met no criteria for assessment.

### Appropriate referrals GRA/ genetic counseling

## Discussion

The Health Heritage decision support tool has the ability to dramatically improve the collection and use of family health history information in the primary care setting. As one part of the user-centered design process, we are characterizing its clinical validity while simultaneously engaging feedback from primary care providers. In the coming months we will conduct additional usability testing with patients.