

# On second thought...Updates to personal and family history using an interactive online tool

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## Introduction

A comprehensive pedigree and health history are central to effective genetic counseling. However, traditional methods for collecting this information have limitations as personal and family histories are usually collected at a single point in time, in conversation with a single person. Previous studies have reviewed various implementations of online health history tools<sup>1</sup> and have demonstrated that patient-directed online tools can have similar accuracy compared to in-person consultations,<sup>2</sup> although completion rates are often low.<sup>3</sup> In all cases, the implementations assumed a single point of contact, with one participating individual.

The clinical laboratory Color Genomics has implemented an online, interactive health history tool that aims to address some of these limitations through direct interaction with individuals, at their convenience, with built-in editability. This tool lets individuals build their own family trees, solicits relevant clinical information, and supports the review and revision of the information at any time and place. It also supports secure and collaborative editing with family members. Here, we report how 40,000 individuals utilized this online, interactive health history tool and how often the collected information changed over time.

## Methods

Individuals included in this study were 40,000 consecutive Color clients who consented to have their de-identified information and sample used in anonymized studies.

All individuals created an online account and progressed through a series of interactive screens that solicit personal and family health information using a series of nested, directed questionnaires. The provided information was assembled into a built-in pedigree. Individuals were also provided the opportunity to invite people represented in the pedigree to collaboratively contribute. In this workflow, individuals had the option to partially complete the process, to save their progress, to return later with additional information, and/or to edit previously reported information. At predefined time points, emails may have been sent to individuals to encourage them to review or complete their health history information.

Interactivity data and revisions made by individuals and invited relatives were logged and compared to proactive outreach emails from Color. Revisions included in this study were revisions to personal health history and revisions to the health history of other relatives within the first year of receiving a genetic testing report.

## Conclusions

- The data presented here clearly illustrate that the creative integration of technology can effectively engage individuals in a critical activity and that there is sustained interest over time in reviewing and modifying family history information.
- Approximately 70% of individuals returned to make revisions to their health history or family tree after the initial session.
  - The majority of people returned almost two weeks later, which coincides with an “in-progress” email from Color.
- Approximately 4% of individuals invite people to contribute to a Shared Family History, and about 10% of invited relatives contributed information.
  - This establishes a baseline for connectivity on which future user interface modifications can be built.
- While this analysis does not address the impact of these changes on the accuracy of the information or on the output of risk models, it does clearly establish that an online platform can effectively support revisions to the record of personal and family history over time.

## References

1. Welch BM, Wiley K, Pflieger L, et al. Review and Comparison of Electronic Patient-Facing Family Health History Tools. *J Genet Couns.* 2018;27(2):381-391.

2. Tipsword ML, White PS, Spaeth CG, Ittenbach RF, Myers MF. Investigation of the Use of a Family Health History Application in Genetic Counseling. *J Genet Couns.* 2018;27(2):392-405.

3. Appleby-Tagoe JH, Foulkes WD, Palma L. Reading between the lines: a comparison of responders and non-responders to a family history questionnaire and implications for cancer genetic counselling. *J Genet Couns.* 2012;21(2):273-291.

## Results

Figure 1. Interactive, online health history tool.

Through the interactive, online health history tool, individuals can provide information about their personal and family health history, including demographics and cancer and cardiovascular disease, to build a family tree.

Have you had (or do you currently have) cancer?

☐ Yes ☒ No

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Have you ever had:

Mastectomy <small>Optional</small>	<input type="radio"/> Yes <input checked="" type="radio"/> No
Oophorectomy <small>Optional</small>	<input type="radio"/> Yes <input checked="" type="radio"/> No
Breast biopsy	<input type="radio"/> Yes <input checked="" type="radio"/> No
Bone marrow transplant or blood transfusion	<input type="radio"/> Yes <input checked="" type="radio"/> No

Have you ever had colon polyps identified on colonoscopy or sigmoidoscopy? Optional

☐ Yes ☒ No ☐ I'm not sure

Have you had a genetic test for hereditary cancer risk? Optional

☐ Yes ☒ No

Figure 2. Revision rate after initial session.

70.8% (28,332) of individuals returned to the interactive, online health history (Hx) tool to make revisions after the initial session (a median of 9 days later). In some cases, this represents revisions to a fully detailed personal and family Hx, and in other cases, this represents people who were unprepared to provide details at the initial session and later returned with those details.

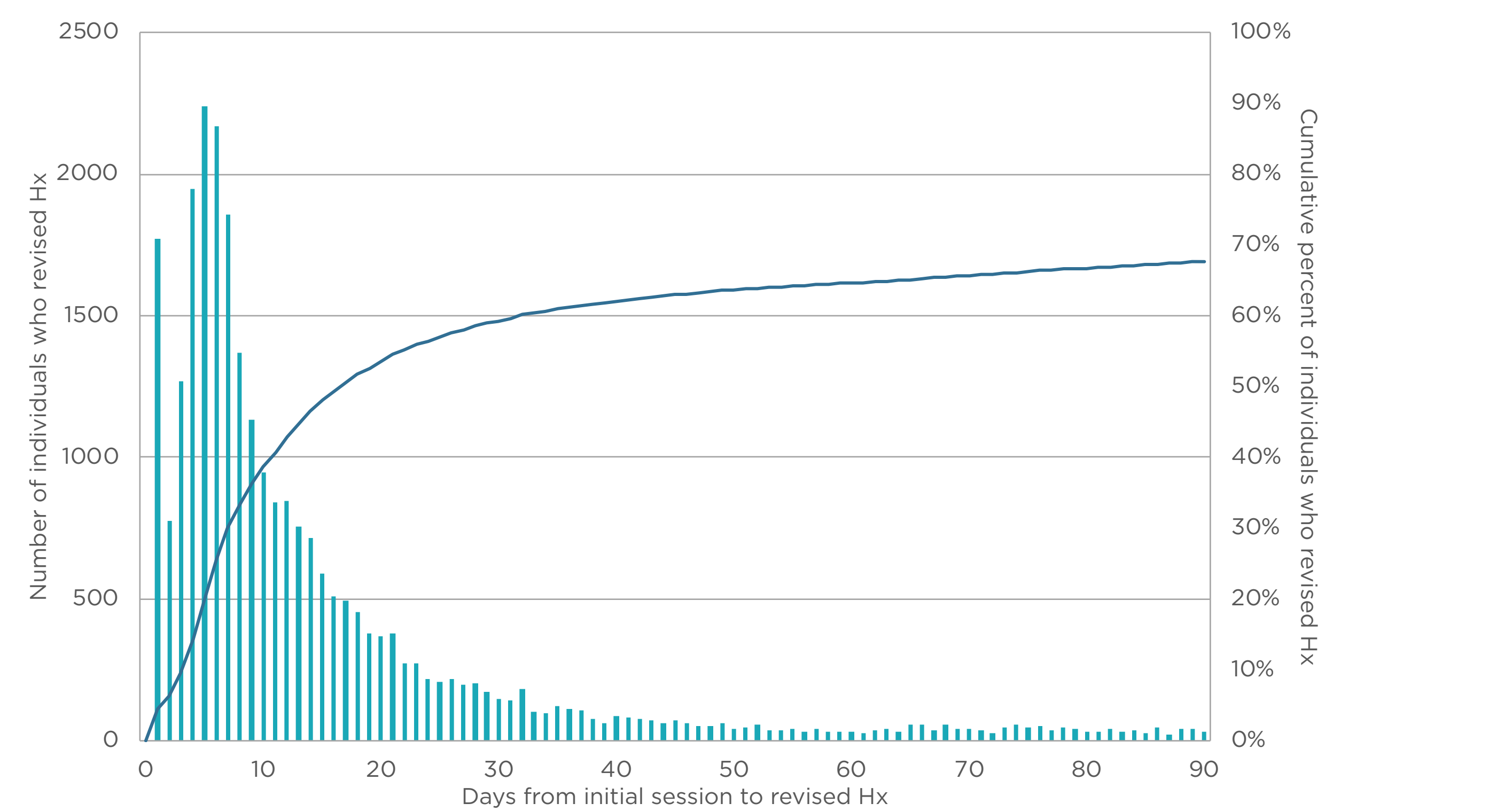


Figure 4. Inviting relatives to Shared Family History.

Through the interactive, online health history tool, individuals can invite relatives to collaborate on their family tree. Importantly, relatives cannot edit the individual's information or see the individual's Color results.

HEALTH CHECK > HEALTH HISTORY > FAMILY TREE > FAMILY HISTORY > INVITE

Invite relatives to collaborate (optional)

By inviting your relatives to a Shared Family History, you can increase the quality of your family health information while helping your relatives do the same.

What information will be shared with my relatives?

Mother (55)	Email address
Maternal Grandmother (85)	Email address
Paternal Grandmother (85)	Email address

Save Without Inviting

### About Shared Family History

**Relatives will be able to**

- Invite other relatives
- See only visible information
- Edit relatives' information
- Can't edit your information

**Visible Information**

- Your name and age
- Relatives' names and ages
- Disease history you entered
- Can't see your Color results

Got It

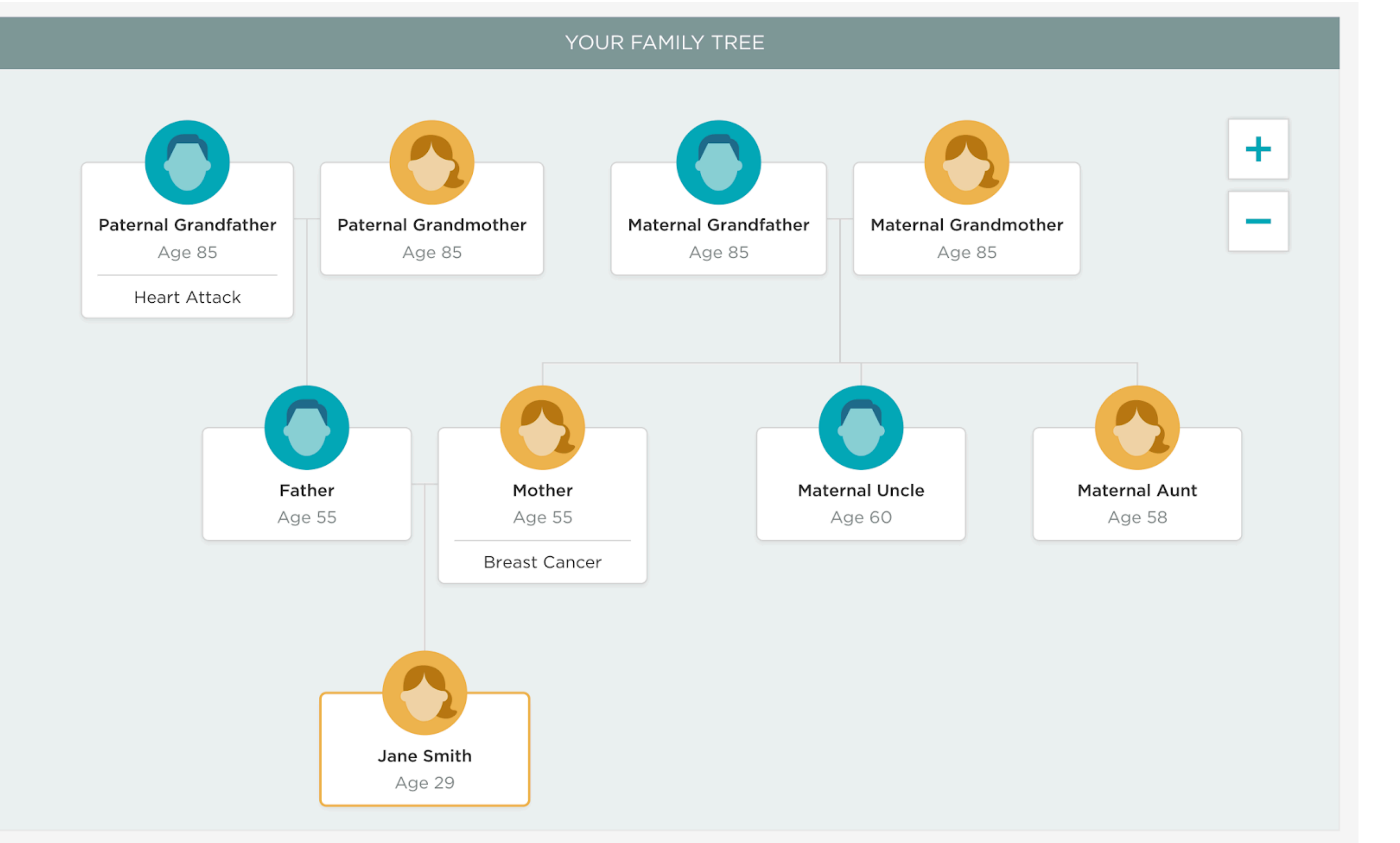
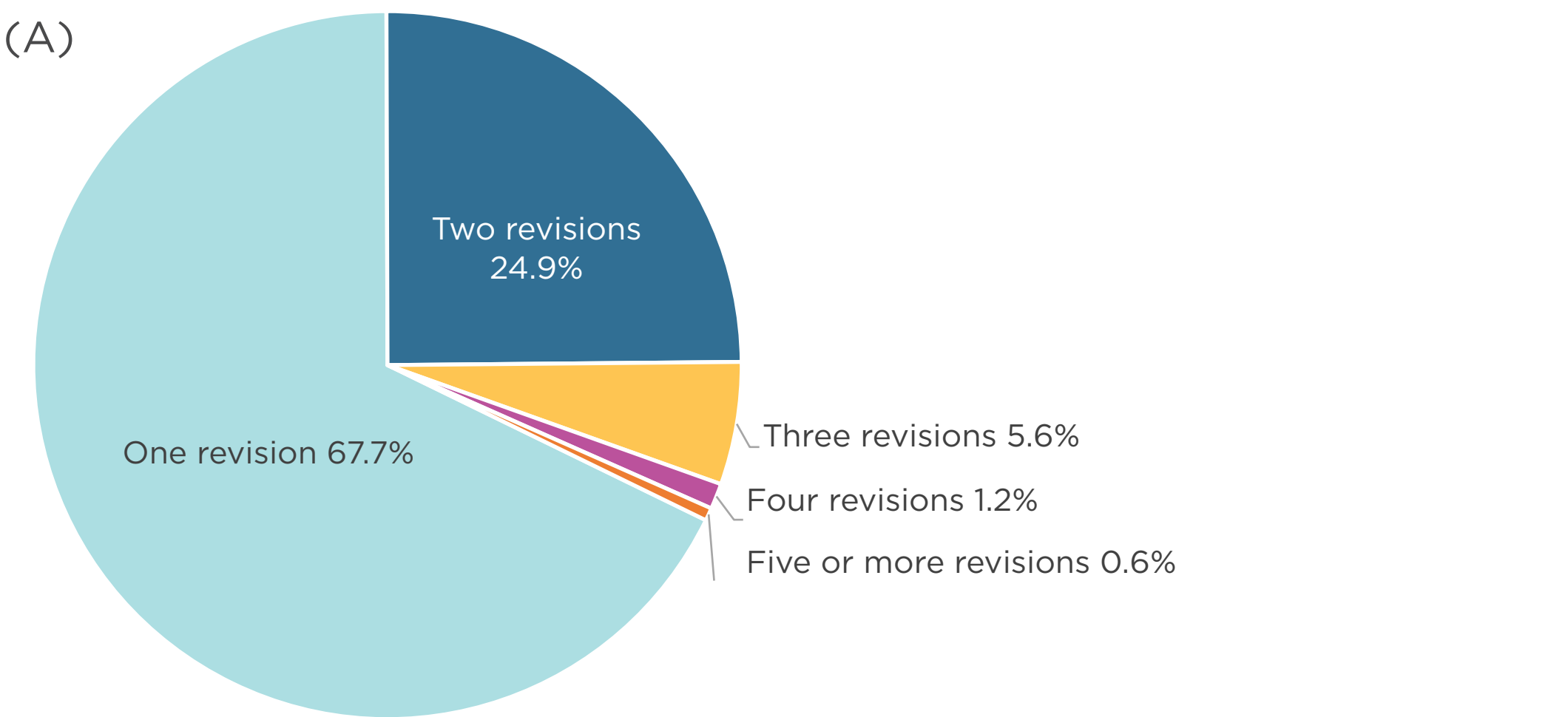


Figure 3. Number and types of revisions made by individuals.

(A) Of those individuals who made revisions, nearly one-third (9144) of individuals made revisions more than once in a one year period.



(B) Of those individuals who made revisions, 25.6% (7246) of individuals made revisions to their personal health history (Hx). However, 91.8% (26,021) of individuals made changes to family Hx, suggesting that subsequent conversations after the initial session may identify other relevant information.

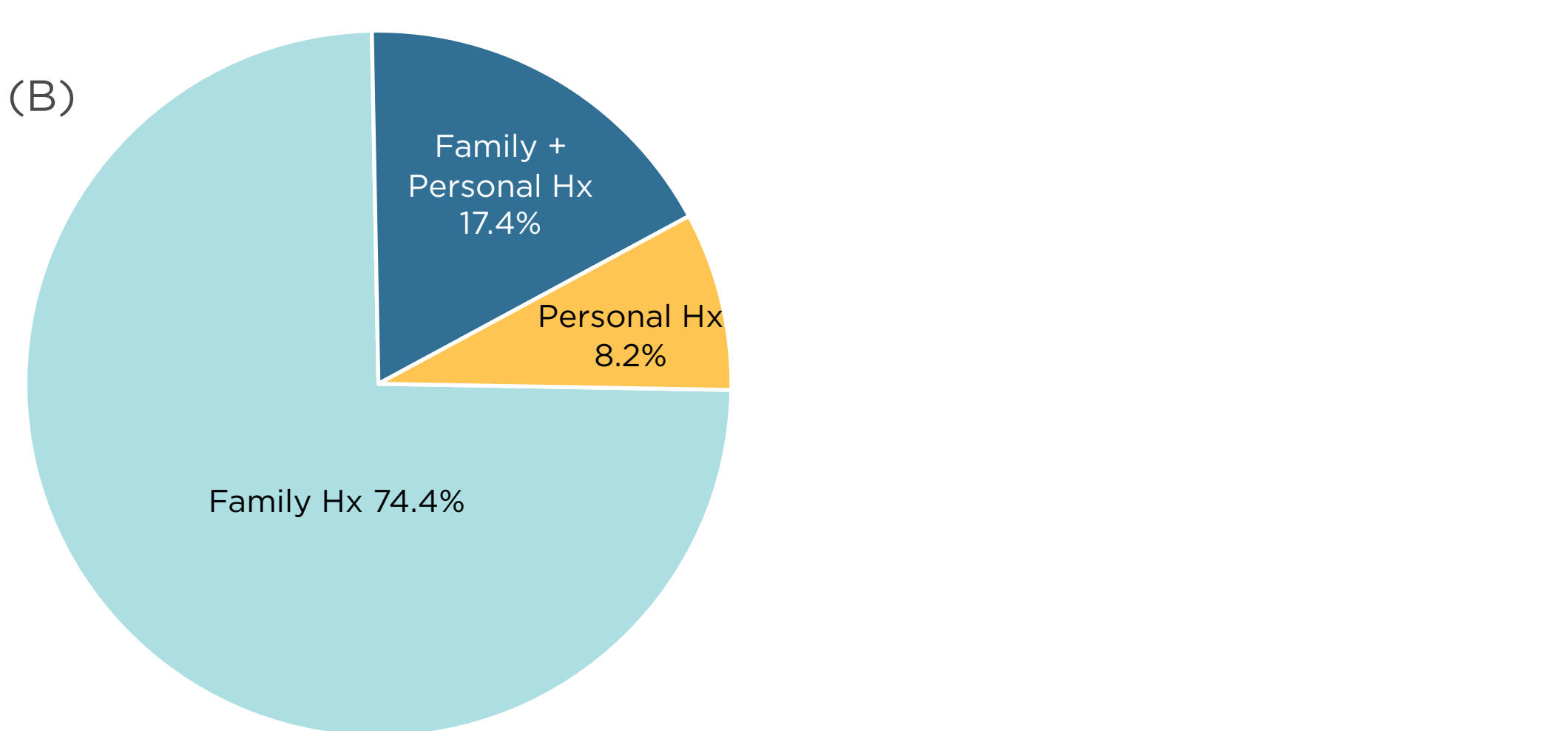


Figure 5. Types of revisions made by invited relatives.

1447 individuals invited 3602 relatives to collaborate on a Shared Family History (approximately 2.5 invitations/individual). Of the 751 (20.8%) relatives who accepted the invitation, more than one-quarter of relatives made revisions to their own health history and more than one-quarter of relatives made revisions to the health history of another relative.

