FH Family Share— A Web-based Tool for Familial Hypercholesterolemia
Cascade Testing and Knowledge Dissemination

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Introduction

Familial Hypercholesterolemia (FH), an autosomal dominant genetic disorder, increases the risk of premature coronary heart disease including myocardial infarction. Cascade testing for early diagnosis of FH has limited uptake in the US and the yield is low using conventional methods for contacting relatives1. Innovative digital tools may lower barriers to cascade testing by facilitating family communication.

Methods

Nine genetic counselors participated in usability testing to validate a web-based tool—“FH Family Share.” The tool was designed to: a) facilitate cascade testing using templated emails to allow for faster communication between FH probands and family members; b) using a family tree tool to build pedigrees and identify at-risk relatives and c) promote knowledge dissemination through learning modules and resources. Counselors were asked to assess educational content and interface design by navigating the tool using the “Think Aloud” usability technique. They provided insights on how the tool would fit their clinical workflow and completed a brief 7-item satisfaction survey.

Results

Usability testing with counselors resulted in key workflow insights and highlighted specific modifications that could be made to FH Family Share (Figure). Survey analysis revealed that 66.7% of counselors found information ‘very easy to find’ within FH Family Share and 55.6% of counselors found information ‘very easy to understand,’ All counselors found FH Family Share to be a resource worth returning to.

Figure: Genetic counselor workflow validation (left column) and usability testing findings (right column).

Conclusion

We describe the creation of a website to facilitate cascade testing for FH by improving communication between FH probands and their family members, thereby leading to earlier disease detection and treatment. FH Family Share will undergo further refinements and additional usability testing prior to its implementation into clinical practice.

References