

The use of software can address workforce shortage and access barriers to genetic counseling

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Introduction

Since the discovery of *BRCA1* in 1994, the prevalence and uptake of germline genetic testing for hereditary cancer has increased dramatically¹. As a result, clinical genetics providers have struggled to keep up with the rising demand. Previous analyses of time-based efforts have determined that clinical genetics services are time consuming and labor intensive, with as little as 25% to 41% of a genetic counselor's time spent on direct client care and up to 3.5 to 7 total hours spent per client²⁻⁶. To reduce barriers to accessing clinical genetics services, alternative delivery models, such as telephone-based counseling (reviewed in⁷), have emerged and have been shown to be as effective as in-person delivery. Here, we present a novel service model that utilizes software and technology to deliver genetic services in a more streamlined and efficient manner. Through this model, genetic counselors spend drastically less time than industry averages conducting non-direct client care activities, thereby increasing the proportion of time spent on direct care and availability for more clients.

Methods

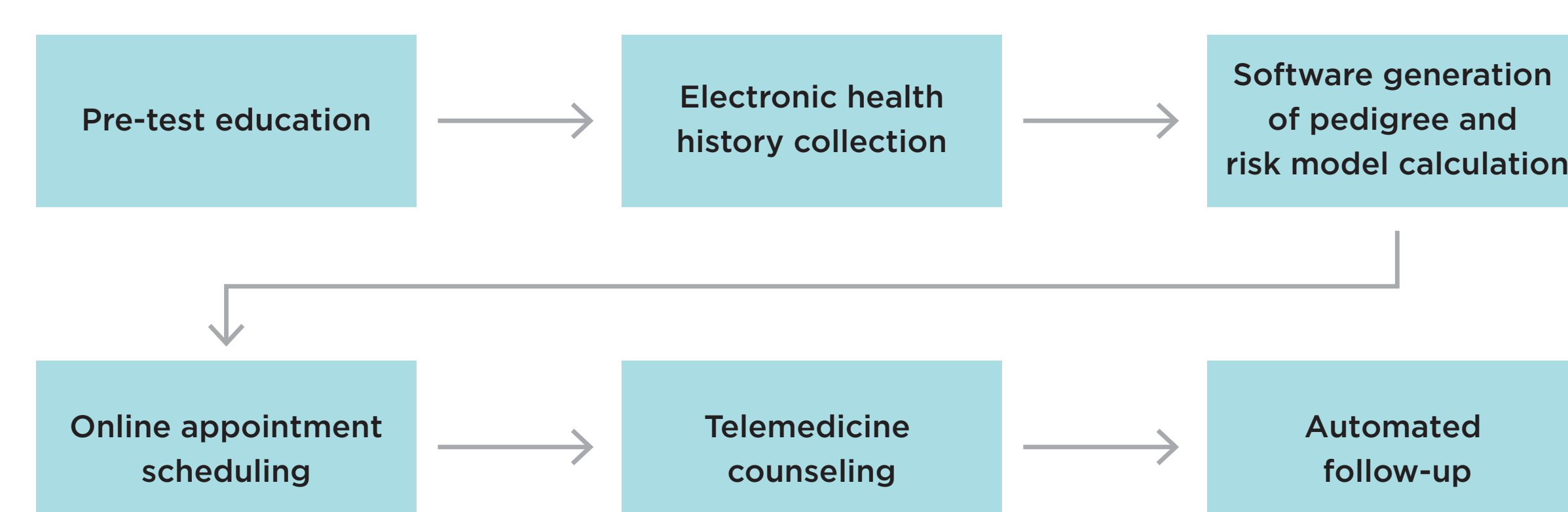
All individuals were referred by physician order for the Color Hereditary Cancer Test to detect gene variants associated with hereditary cancer. The majority of genes were assessed for variants within all coding exons and non-canonical splice regions. Laboratory procedures were performed at the Color laboratory under CLIA and CAP compliance. Variants were classified according to the American College of Medical Genetics and Genomics 2015 guidelines for sequence variant interpretation⁸, and all variant classifications were approved by an American Board of Medical Genetics and Genomics board certified medical geneticist. Pathogenic and likely pathogenic variants were confirmed by an orthogonal technology (Sanger sequencing, aCGH, or MLPA). Results were reported positive if one or more pathogenic/likely pathogenic variant was detected and negative if no variant and/or only benign or likely benign variants were detected. Variants of uncertain significance (VUS) were counted as negative reports.

For the time-use studies, genetic counselors tracked time spent providing direct patient care, such as speaking directly with patients by phone, and conducting non-direct patient care activities, such as preparing for the appointment, reviewing health history, making notes in chart, and writing patient letters. The study duration was July 2015 through April 2017 and included over 1800 unique post-test telephone-based genetic counseling sessions. Average time spent on risk model calculation was tracked by support staff and genetic counselors from January 2016 through November 2016.

Appointment wait times were estimated by measuring the time elapsed from when a client submits an appointment request through the appointment scheduling software to when their appointment took place. Online health history questionnaire completion was measured for all clients who received a genetic counseling appointment.

Figure 1. Genetic counseling workflow

Clients are offered pre-test education through an online video and website content. Clients provide their health history via an online questionnaire, and in-house software generates a pedigree and calculates risk models. Clients then schedule a telephone-based genetic counseling session through an online system. Following the session, secure electronic notes are sent to the clients and their providers, and a one-month follow-up email is automatically generated.



Results

Figure 2. Technology integration across the genetic workflow

We delivered post-test telephone counseling using supportive technology and spent an average of 37 minutes per patient, with 53% of that time spent on direct client care. Data from previous studies of traditional models is presented as reported^{2,4,5} or extrapolated based on reported information⁶.

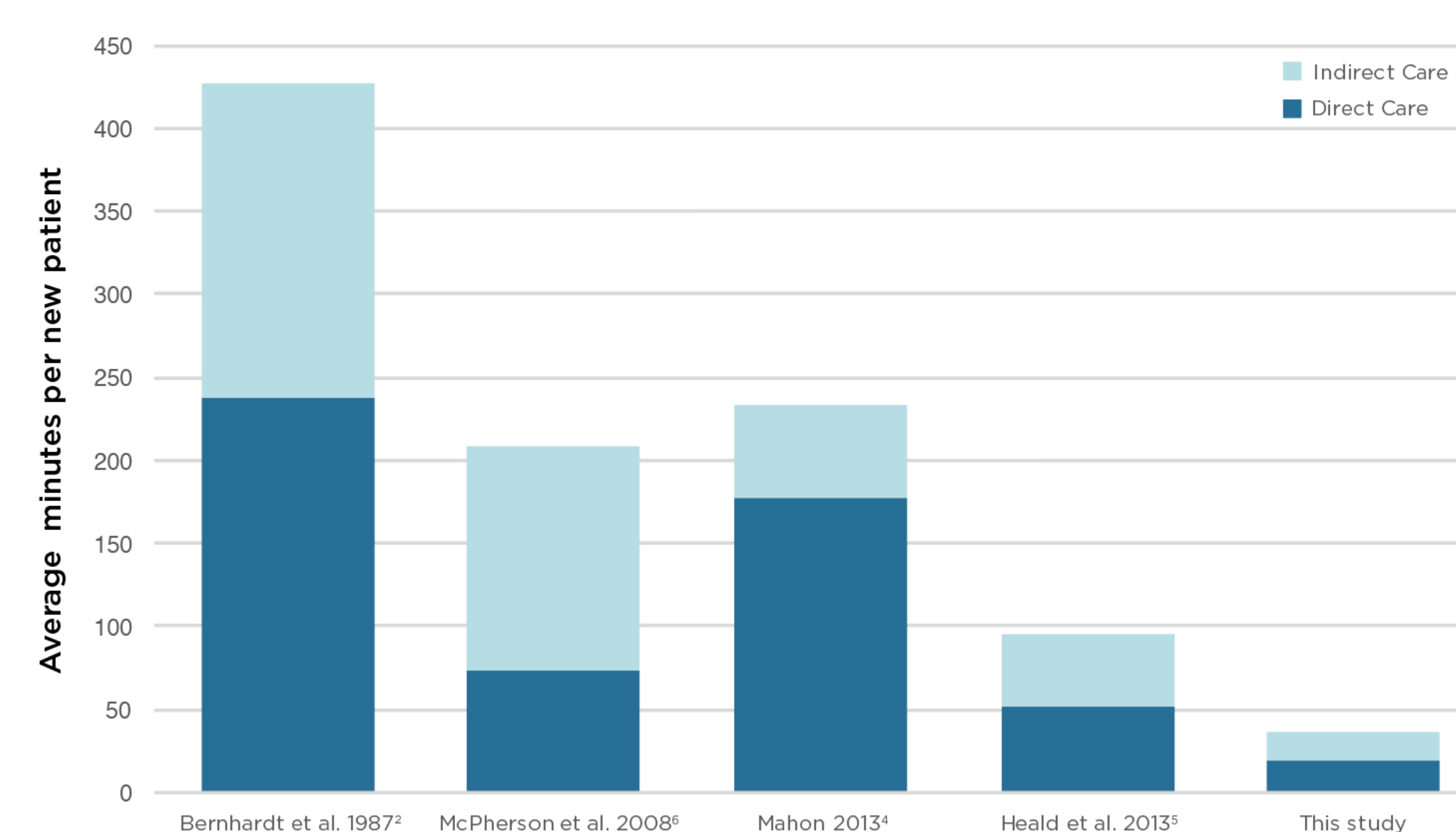
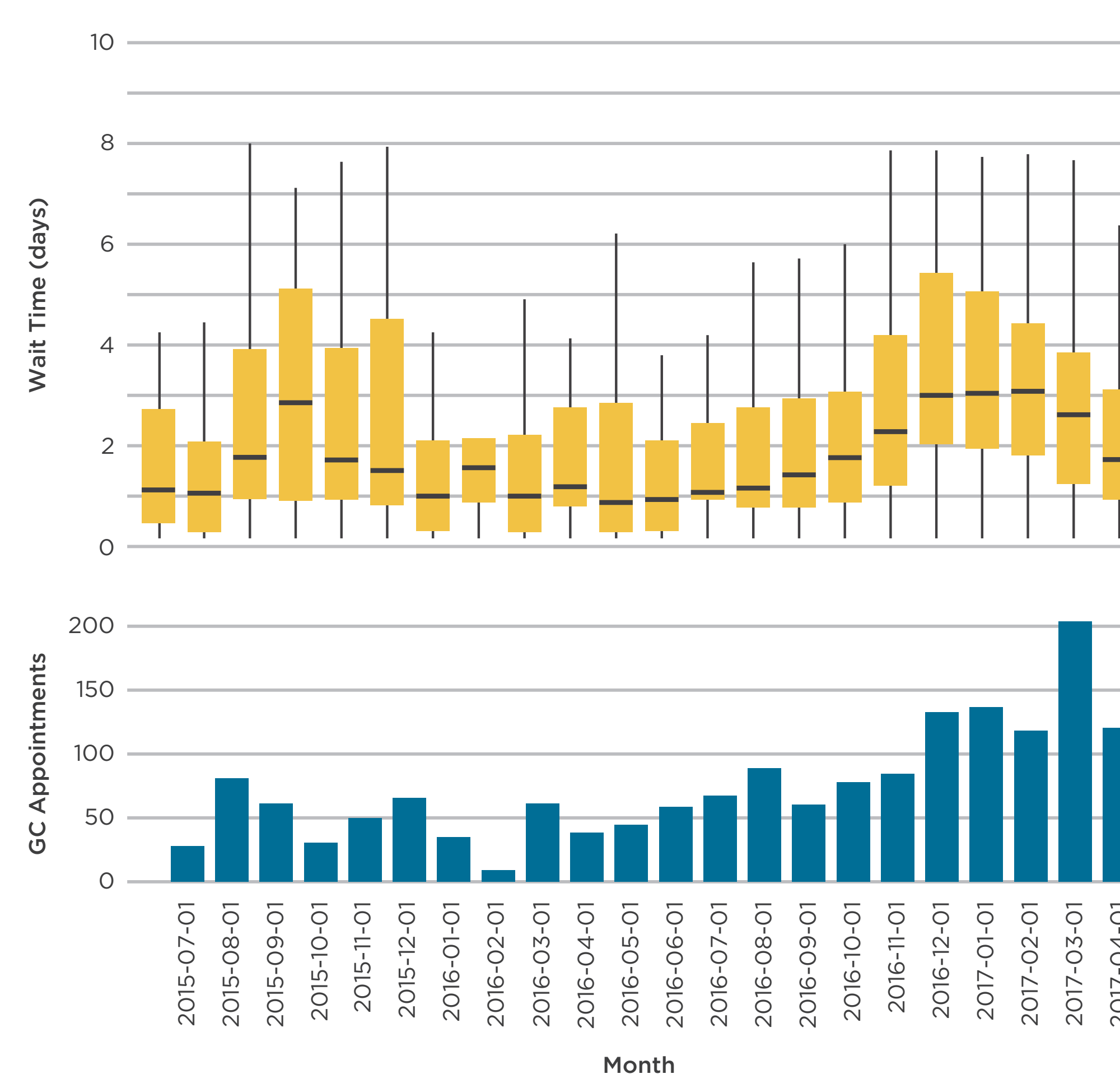


Figure 3. Appointment scheduling

Using online software to manage client appointments allowed us to easily facilitate increases in monthly GC appointment volume without increases in client wait times.



Conclusions

- Customized, automated software can improve access to genetic counseling. Remote counseling is not geographically constrained, can be adapted to changes in volumes, and is relatively low in cost. Additionally, scheduling software allows allocation of sessions across a large genetic counseling team, keeping wait times fairly consistent regardless of large and variable client volumes.
- Client satisfaction and experience can be improved by automation. For example, our databases keep track of any future changes in information or recommendations that the client or their provider needs to be made aware of, affording an ongoing and up-to-date experience.
- Finally, in addition to meeting rising demand, the software solutions described here utilize genetic counselor and other staff time more efficiently, enabling a cost-savings that we can pass on to our clients.

Figure 4. Genetic counselor time use

Genetic counselors spent slightly more time with clients who received a positive result (40 minutes) compared to those that received a negative (neg) result (30 minutes).

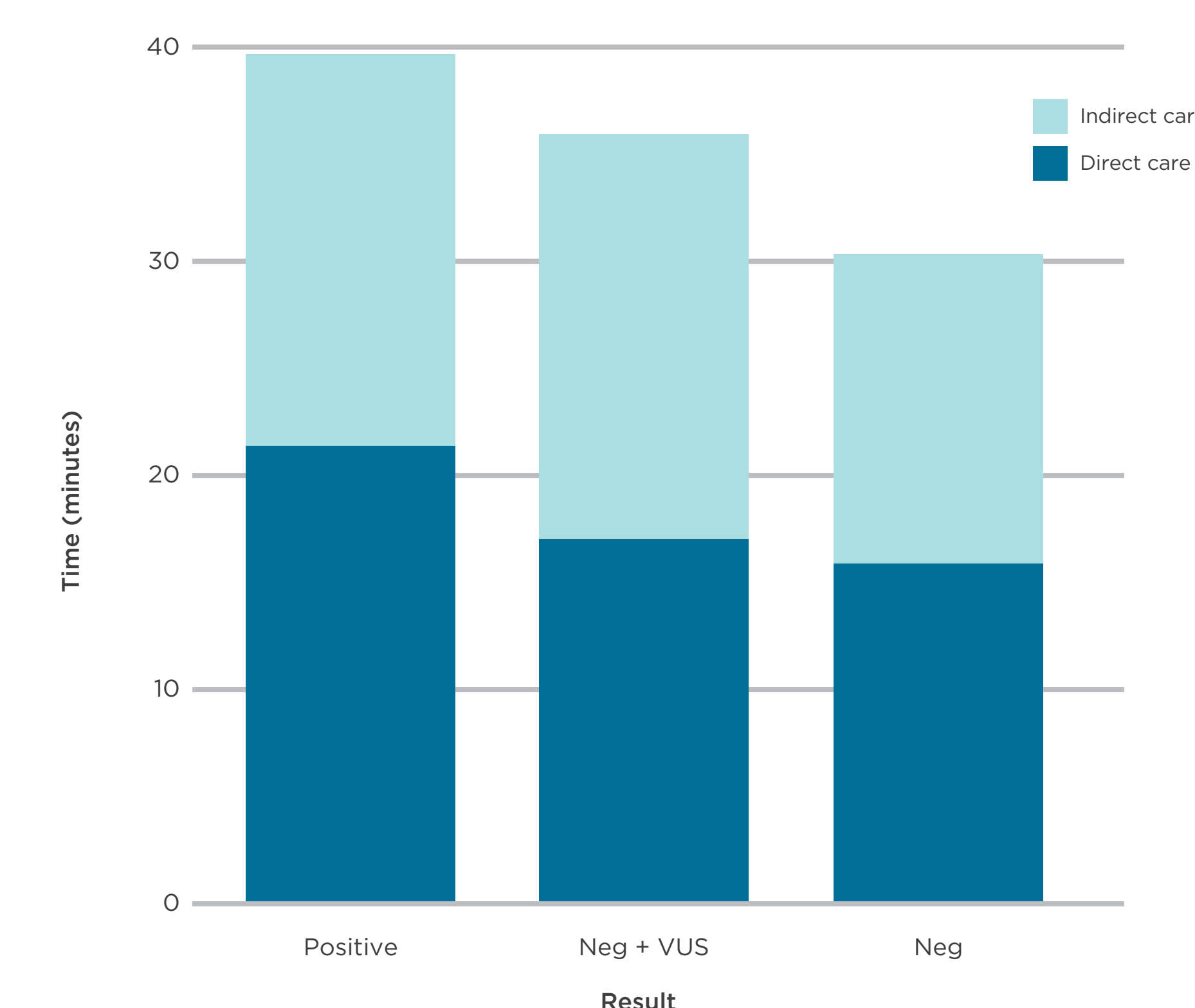
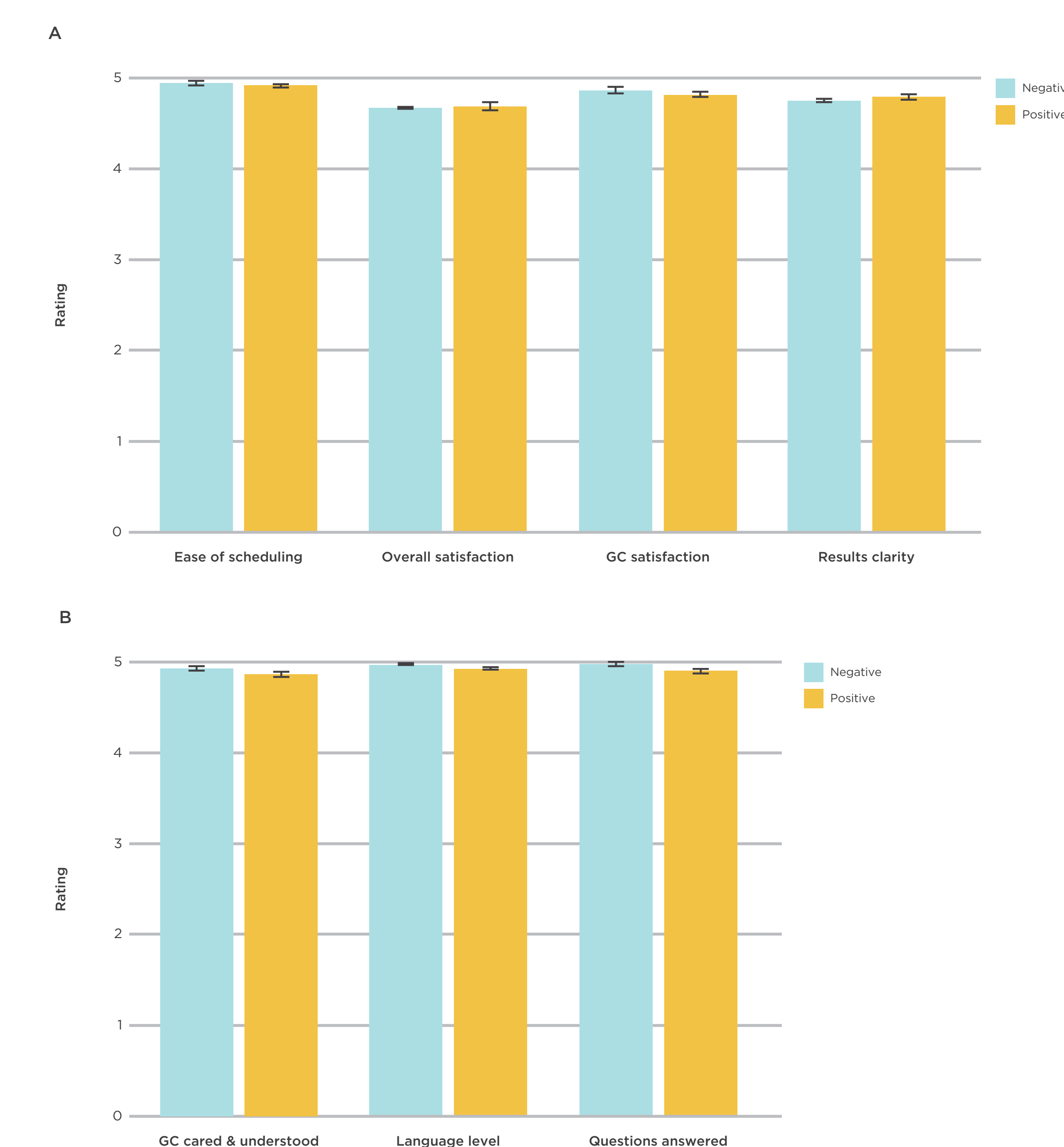


Figure 5. Client satisfaction

Client satisfaction with our genetic counseling services ranged from 4.7 out of 5 to 4.9 out of 5 in an online survey completed by clients after their genetic counseling session. These results were consistent among individuals with positive or negative results. Scale from 1 (very dissatisfied) to 5 (very satisfied).



References

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