

High satisfaction with genetic counseling using telephone-based delivery method for return of results: A pilot



Lily Servais*, Adriana Boateng-Kuffour*, Anjali D. Zimmer, Cynthia L. Neben, Carmen Lai, Julian Scharman, Alicia Y. Zhou
Color Genomics, Burlingame, CA

Introduction

Satisfaction is an important patient reported outcome (PRO) in genetic counseling (GC) that is taken into account when determining the quality of GC services.¹ To improve access to genetic counseling, alternative delivery models, such as telephone-based counseling, are continually being used and have proven to be as effective as in-clinic delivery.²

Color offers an alternative delivery model for genetic testing with access to board-certified GCs included as part of every test. Color's technology-integrated GC model streamlines the administrative processes, and as a result, Color GCs spend drastically more time on direct-care compared to their in-clinic counterparts. For example, compared to the industry average of 3.5-7 hours,³⁻⁵ Color's GCs spend an average of 40 minutes per participant resulting in over 50% time on direct-care. In addition, Color's GC services are higher volume (20-30 consults/GC/week) compared to the majority of in-person clinics (12 consults/GC/week).

While literature on GC satisfaction for in-person clinics reports high patient satisfaction ratings,⁶⁻⁸ satisfaction with telephone-based GC has yet to be evaluated. In this study, we sought to assess participants' level of satisfaction with interactions with Color's telephone-based GC model.

Methods

We administered an online survey to individuals ages 18-75 who consulted with a Color GC from October 2018 - April 2019. All individuals were referred by physician order for a Color test that included genes associated with hereditary cancer risk. 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 interpretation⁹, and all variant classifications were approved by an American Board of Medical Genetics and Genomics board certified medical geneticist.

Results were reported as positive if one or more pathogenic/likely pathogenic variants were detected and negative if no pathogenic/likely pathogenic variants were detected. Variants of uncertain significance (VUS) were reported if identified in either negative or positive reports.

Figure 1. Technology integration across the GC workflow

Prior to genetic testing, Color offers clients access to pre-test educational modules, one-on-one pre-test genetic education with a genetic counselor, and a health history survey to complete. An in-house software generates a pedigree and calculates the individual's risk model scores (such as Claus and Gail, if applicable) using responses from the health history survey. Genetic counseling appointment scheduling and/ or re-scheduling is through an online appointment-scheduling system. Following each GC session, Color generates and sends both clients and healthcare providers electronic notes from the session. Periodic follow-up emails are automatically generated and sent to clients to remind them about important next steps such as sharing results with healthcare providers and family members. In addition, Color proactively recontacts clients with clinical updates including but not limited to: changes in screening guidelines, variant reclassification, new risk information, and advances in genetic testing.

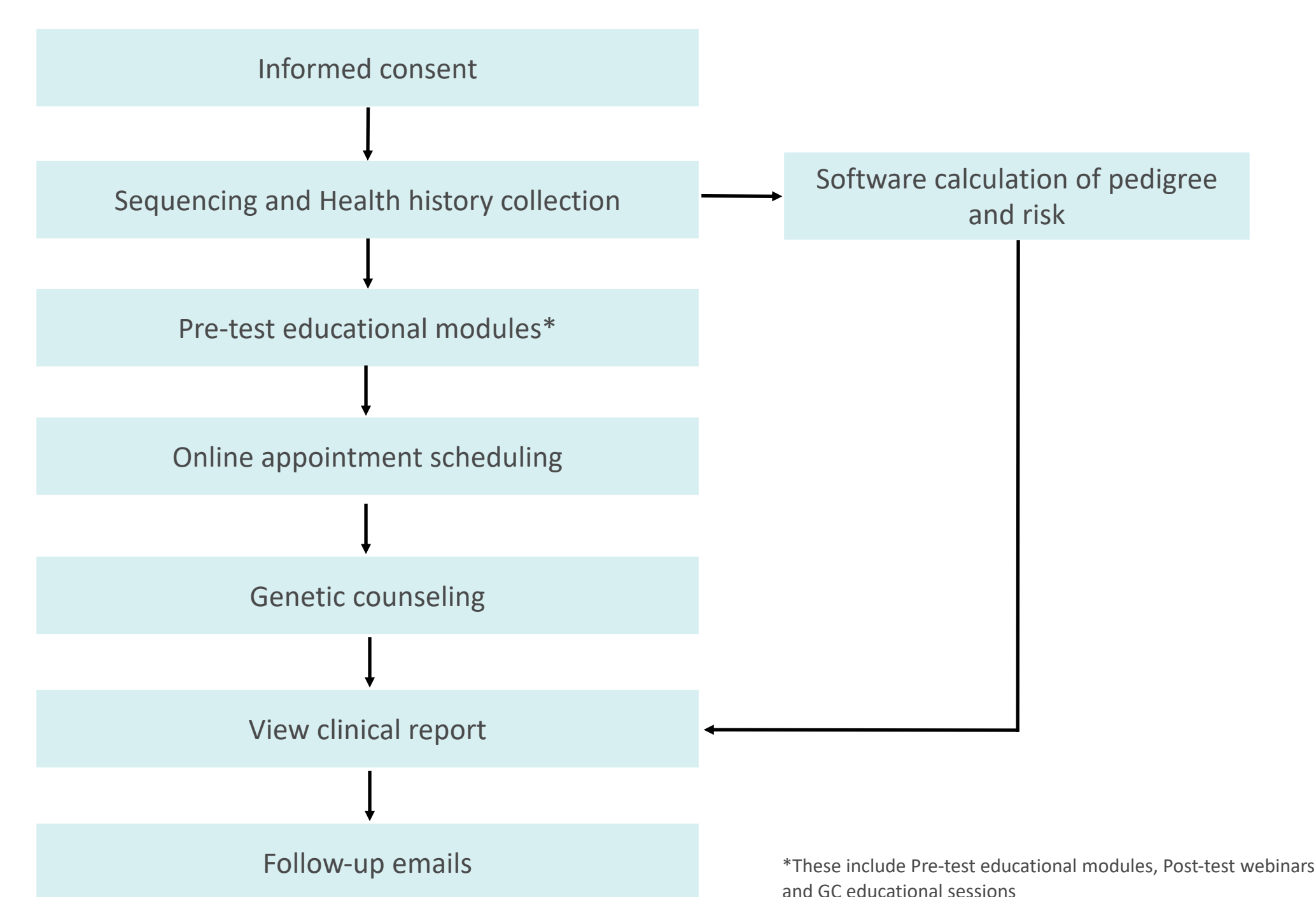
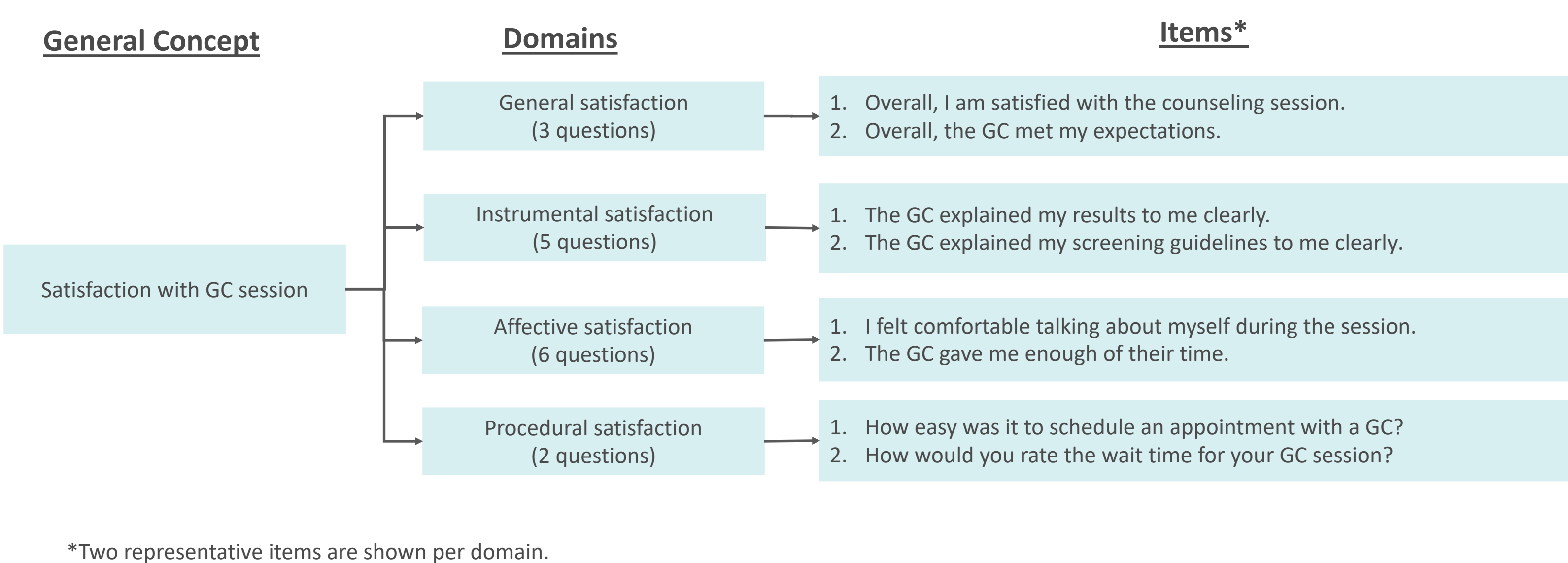


Figure 2. Conceptual framework for questionnaire development

Participants' rated their satisfaction on four domains -- general satisfaction (general feeling of satisfaction with the consult), instrumental satisfaction (extent to which the GC had the required skills and provided the necessary information), affective satisfaction (evaluation of whether the participant felt that the GC was personal and empathetic in the session, versus robotic and rehearsed), and procedural satisfaction (satisfaction with the administrative processes) -- on a five-point linear GC satisfaction scale.¹⁰ To ensure that participants understand the survey questions, we assessed content validity of the adapted questions through semi-structured interviews prior to fielding the questionnaire.



*Two representative items are shown per domain.

Results

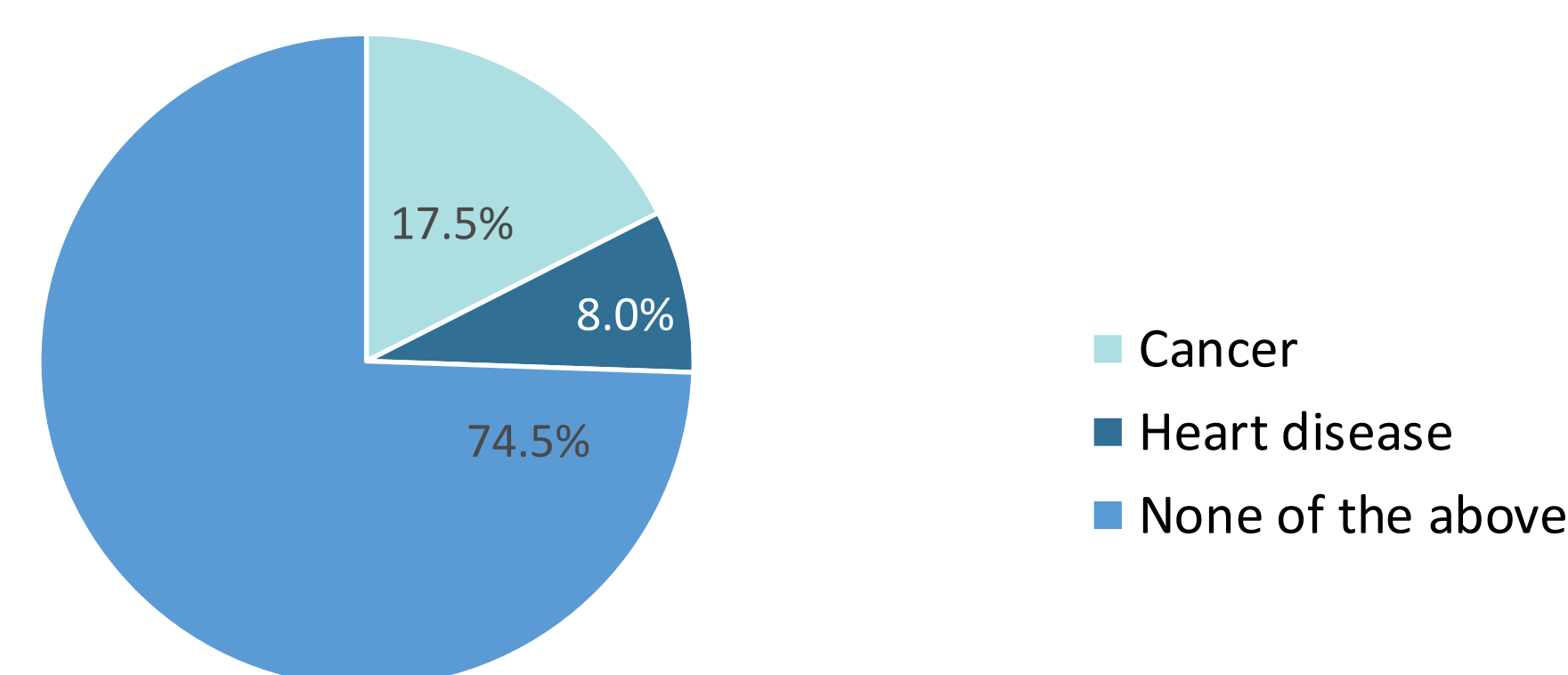
Table 1. Participant characteristics

Majority of participants were 35 years of age or older (81%), Caucasian (88.3%), and college educated (75.9%).

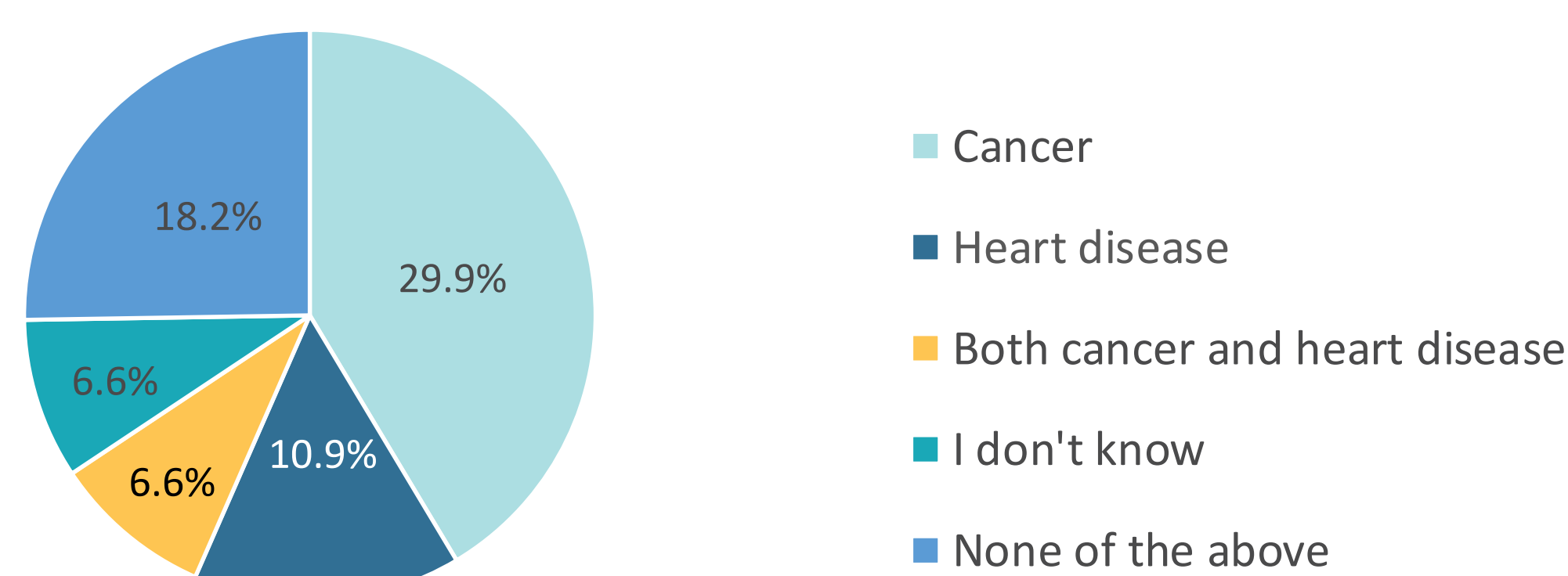
		Participants (n)	Population (%)
Total		137	100
Age (Years)	18 - 24	6	4.4
	25 - 34	20	14.6
	35 - 44	22	16.1
	45 - 54	28	20.4
	55 - 64	34	24.8
	65+	27	19.7
Ethnicity	Hispanic	3	2.2
	Not Hispanic	134	97.8
Race	Asian	7	5.1
	Black or African American	2	1.5
	White or Caucasian	121	88.3
	Mixed race	5	3.6
	Prefer not to answer	2	1.5
	High school graduate or equivalent	3	2.2
Education	Some college, no degree	14	10.2
	Associate degree	16	11.7
	Bachelor's degree	51	37.2
	Graduate or professional degree	53	38.7
Personal history	Cancer	24	17.5
	Heart disease	11	8.0
	None of the above	102	74.5

Figure 3. Cohort characteristics

(A) Majority of the participants did not report a personal history of cancer or heart disease (n=102, 74.5%)



(B) Majority of the participants reported either having a family history of cancer or heart disease (n=65, 47.4%).



Conclusions

- Satisfaction was high across all four domains, suggesting that telephone-based GC can be used to administer counseling to large populations.
- Satisfaction of participants with a positive result was not impacted by the requirement to speak with a GC prior to viewing their results.
- Additional research in a larger cohort would be useful in elucidating further trends in satisfaction as well as assessing any potential relationship between perceived risk and satisfaction among individuals receiving telephone-based GC.

Figure 4. Satisfaction ratings across domains

Average satisfaction ratings were 4.6/5.0 for general satisfaction, 4.6/5.0 for instrumental satisfaction, 4.6/5.0 for affective satisfaction, and 4.4/5.0 for procedural satisfaction.

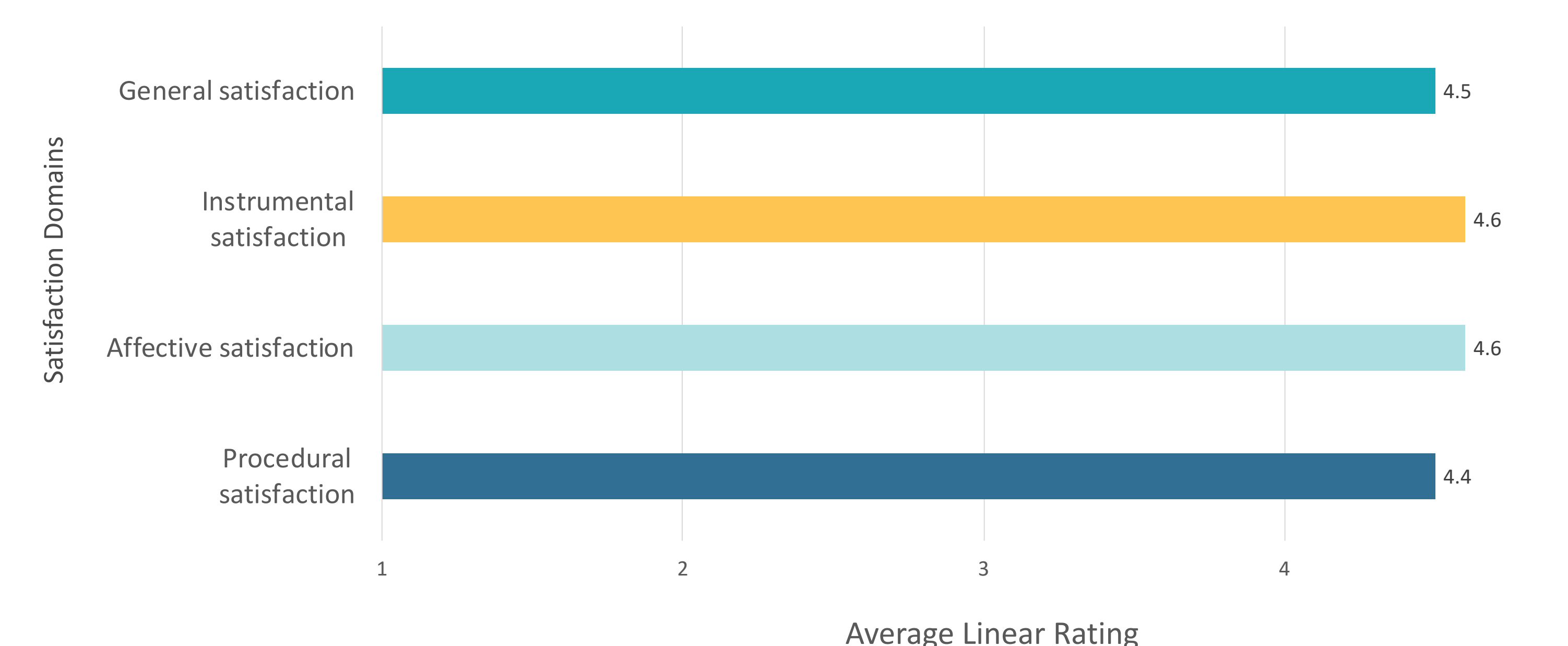


Figure 5. Satisfaction ratings by report type

More than half of the participants within the cohort received a positive result (a pathogenic/likely pathogenic variant identified; n=83, 60.6%). Satisfaction rating was high among positives (n=83, 60.6%) across all domains except for procedural satisfaction. Level of agreement was based on a rating of 4 or 5 on 5-point Likert scale.

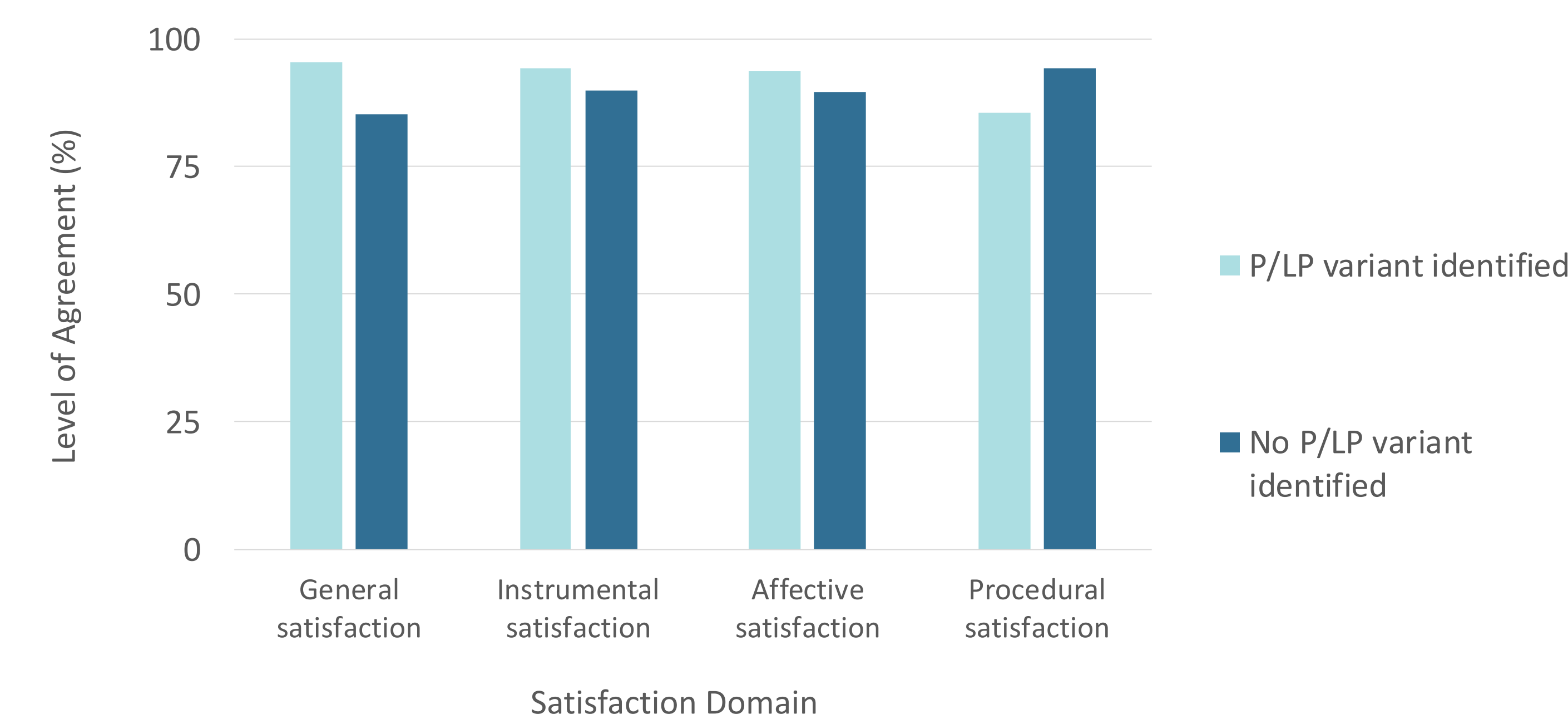
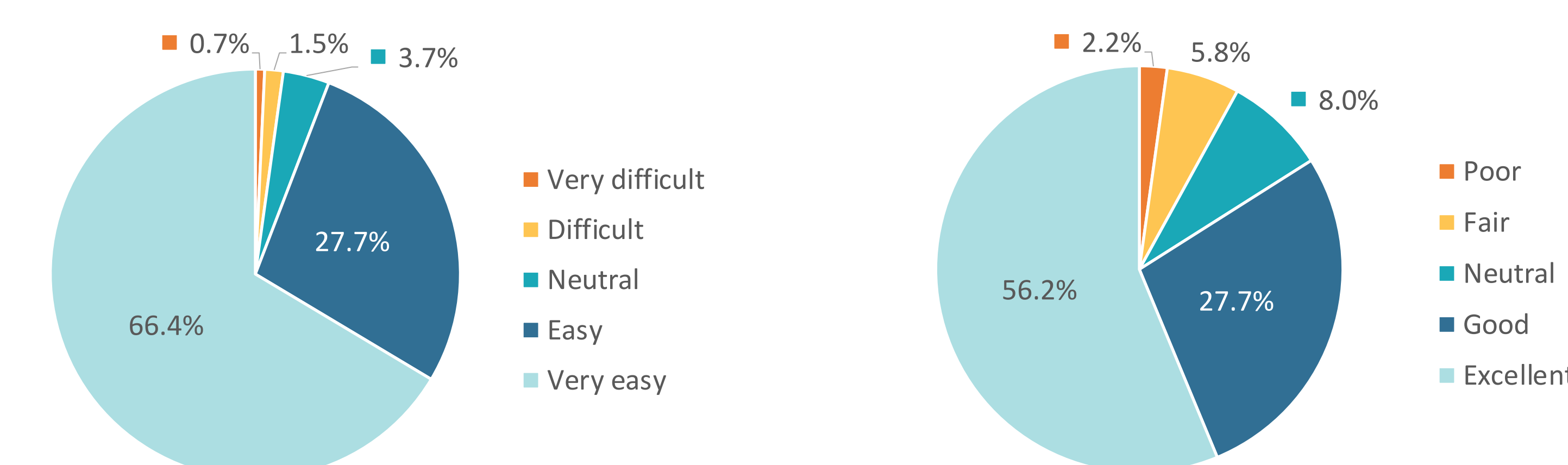


Figure 6. Procedural satisfaction

Procedural satisfaction was assessed based on two variables: ease of scheduling and appointment wait-time.

(A) The majority of the participants (94.1%) found it easy to schedule their GC appointments.

(B) In addition, 83.9% of participants within the cohort reported their wait-time as either good (27.7%) or excellent (56.2%)



References

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