

Interactive Web-based Genetic Screening Questionnaires in a Primary Care and Obstetrics Practice: A Pilot Study

J. A. Neidich¹, C. Taswell¹, and K. Daniels²

¹Global TeleGenetics, Inc., Palo Alto, CA

²Stanford Health Services, Packard Children's Hospital, Stanford, CA

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Introduction

- Research on the genetic basis of disease builds our medical knowledge base.
- New developments in clinical genetics should also reach the patients whose health may benefit from such knowledge.
- Primary care physicians and other healthcare providers usually act as the gateway to genetic consultation or testing.
- Many primary care providers have minimal formal training in genetics or otherwise may not be up-to-date in the field.
- Thus, primary care physicians and many other providers may not know when to refer a patient for genetic services.

Solution

- To assist physicians and other healthcare providers in assessing whether a patient would benefit from genetic consultation, we have developed a series of web-based genetic screening questionnaires for use in primary care settings and obstetrics practices.

Study Methodology

- To test the acceptance of web-based genetic screening by patients and providers, we conducted a pilot study in three primary care settings linked to a major medical center (Global TeleGenetics Clinical Trial 1, or GTGCT1).
- Clinic sites included obstetrics and gynecology and family practice practitioners.

Patient Population

- Clinic patients represent:
 - all racial and ethnic groups,
 - all socioeconomic levels,
 - all levels of educational achievements,
 - a variety of occupations.

Study Protocol

- Of 73 individuals attending these clinics, 59 were approached by their physician or other healthcare worker to extend an invitation to participate in the study.
- Patients were excluded if:
 - they were under 18 years of age,
 - they did not speak English, or
 - their medical condition was too acute for participation.
- The names and ages of all patients who attended clinic were noted.
- All patients who agreed to test the interactive forms signed an informed consent. 50 individuals participated in the study. 14 were excluded and 9 did not wish to participate.

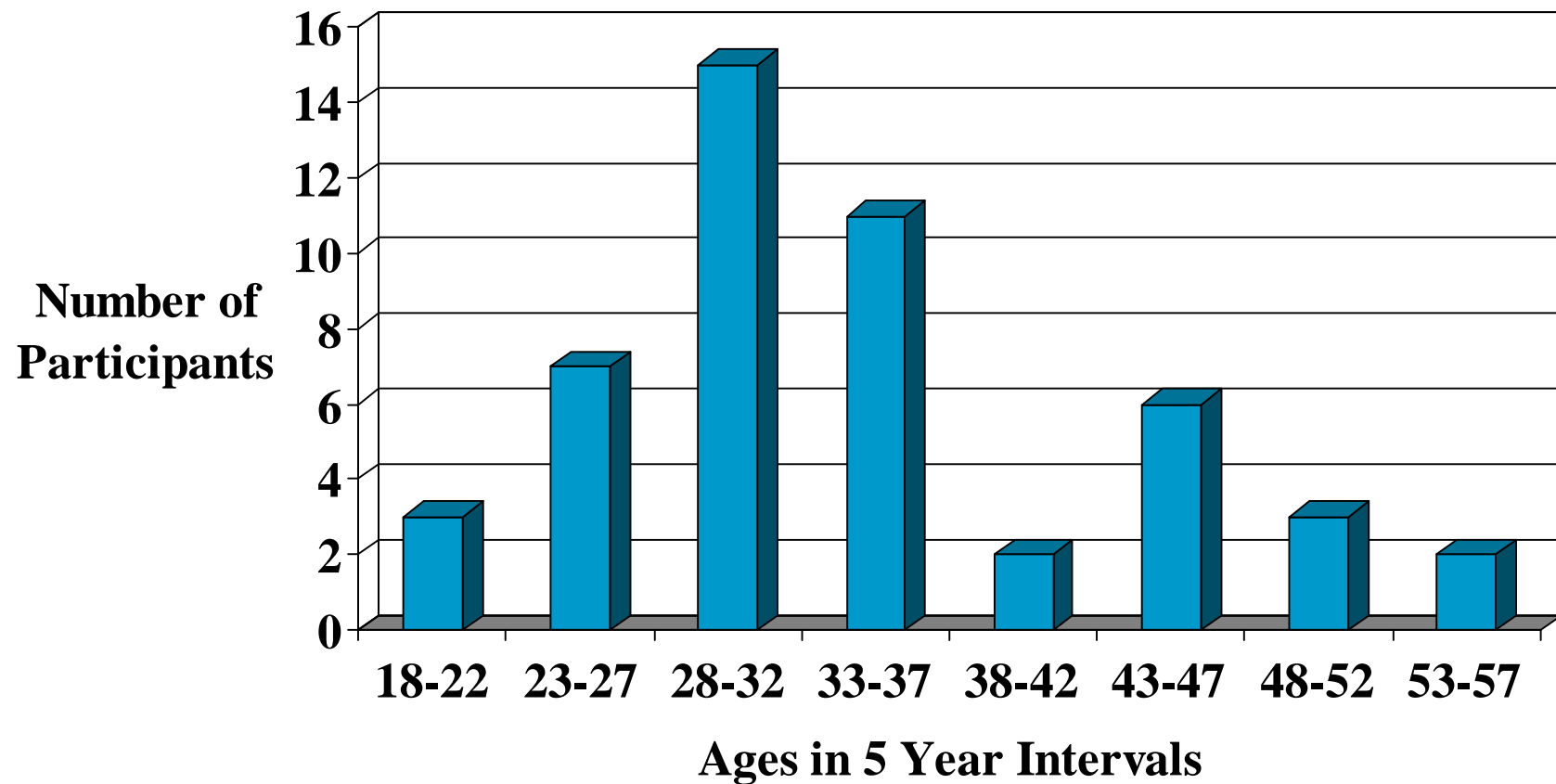
Testing Procedure

- The patients used the same equipment provided by the investigators to complete the interactive web-based forms.
- After completion of the genetic screening questionnaire, all participating patients answered a survey including demographics as well as questions about their experience.
- Patients were then given the opportunity to comment on the forms, computer, and their experience.

Results: Participants' Choices

- Of the 73 potential participants in clinic on the days of the study, 50 agreed to test the forms.
 - 31 selected to complete the form screening for risks during pregnancy.
 - 17 selected to complete the form screening for hereditary risks of breast cancer.
 - 2 selected to complete the form screening for genetic risks of colon cancer.
- Of the 23 remaining individuals, only 9 refused to participate.
 - 📅 7 of the 9 had other appointments.
 - 📅 1 patient stated that she did not know her family history.
 - 📅 1 stated she did not feel well.
 - 📅 14 patients were excluded from participation.

Demographics: Age Range



Demographics: Education

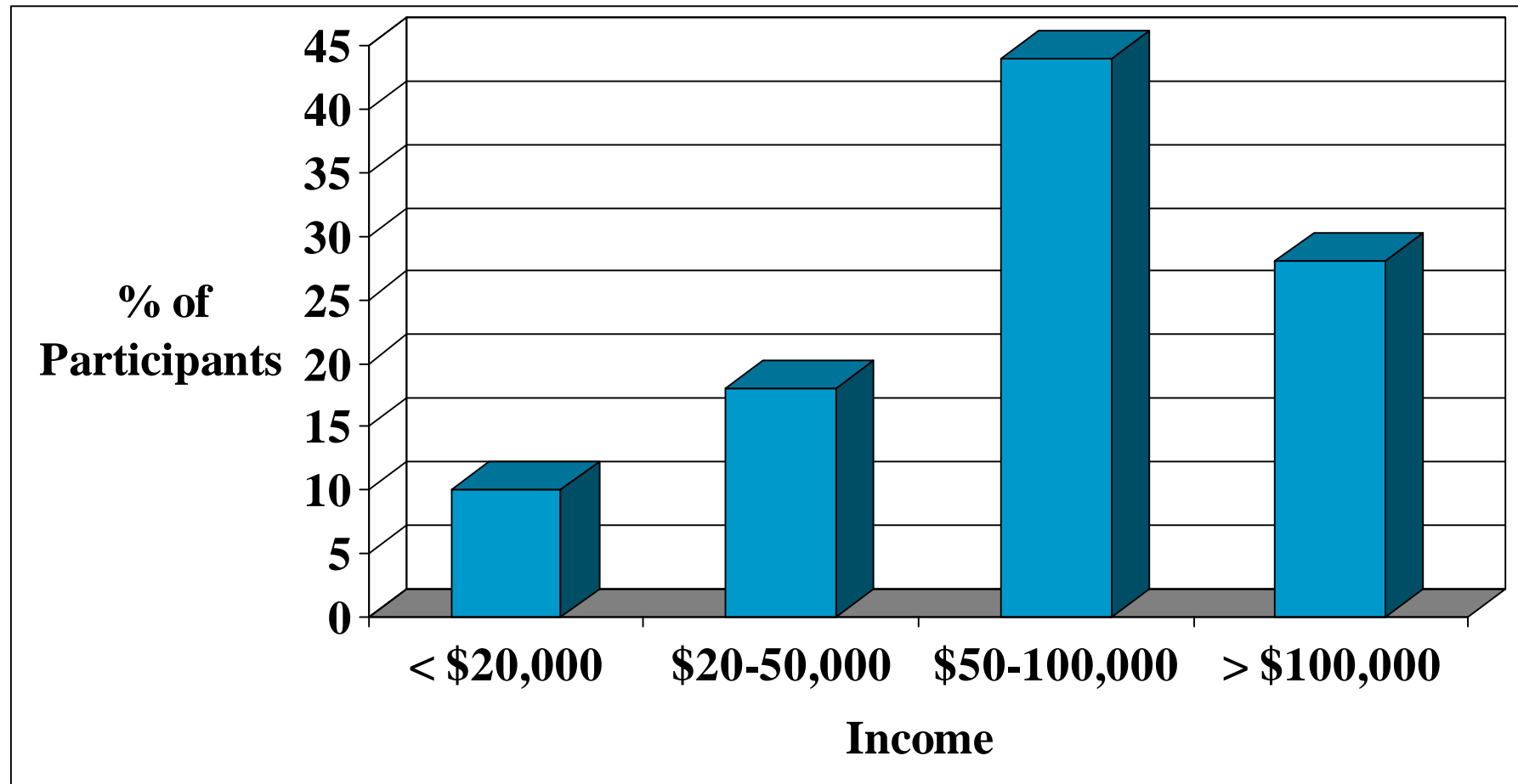
Education	Number	% Participants
No High School	1	2%
Some High School	1	2%
High School Grad	4	8%
Some College	18	36%
College Grad	13	26%
Graduate Program	8	16%
Doctorate	5	10%

Demographics: Occupation

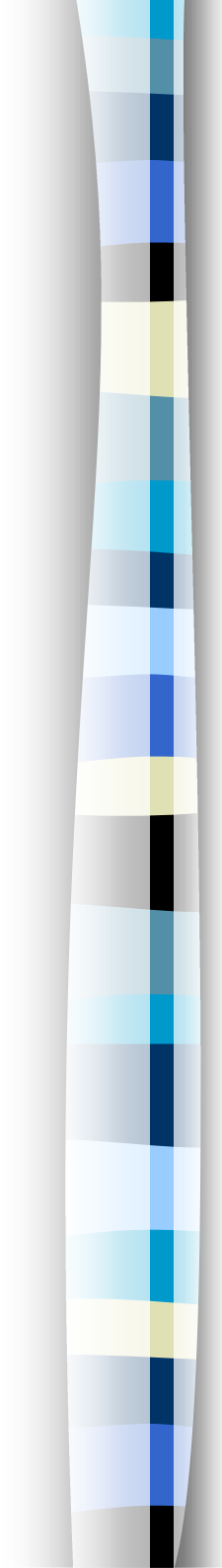
■ Reported occupations included:

– Healthcare worker	10	20%
– Clerical/Office worker	8	16%
– Commerce/retail	8	16%
– High tech/computer science	6	12%
– Management	4	8%
– Physician	4	8%
– Student	3	6%
– Teacher/teacher's assistant	2	4%
– None given	2	4%
– Homemaker	1	2%
– Artist	1	2%
– Unskilled labor	1	2%

Demographics: Family Income



GTGCT1 Participants' Computer Experience



■ None	2%
■ Beginner	12%
■ Intermediate	68%
■ Advanced	18%

Where and How GTGCT1 Participants Used Computers

■ Where

- Home 86%
- Work 86%

■ How

- Use installed programs 72%
- Wrote own program 28%

GTGCT1 Participants' Internet Experience

■ None	6%
■ Beginner	14%
■ Intermediate	68%
■ Advanced	12%

How GTGCT1 Participants Used the Internet

- Shop Online 64%
- News or Financial 64%
- **Medical Information 64%**

Results: Confidentiality Concerns

- Concerns about confidentiality:
 - Completely unconcerned 16%
 - Unconcerned 42%
 - Not important 14%
 - Concerned 20%
 - Very concerned 8%

GTGCT1 GeneScene Screen Satisfaction Ratings

- 100% of the participants agreed (23/50) or strongly agreed (27/50) with the statement “Overall, I was satisfied with my experience.”
- 84% stated they would not object to be screened for other genetic risks.

GTGCT1 Provider Acceptance

- All physicians and staff of the clinics were enthusiastic about the use of screening forms in the evaluation of their patients.

Results: Web-based Forms

- 54% stated that they would prefer to complete an interactive web-based genetic screening form when compared to a paper form or being asked the questions by their healthcare provider. Another 36% did not have a preference.
- Only 6% disagreed that a web-based form would save them time and only 14% would not want to use an interactive form from home prior to a medical appointment.

Results: Ease of Use

- All participants felt the web-based forms were easy to read and only one person had some difficulty seeing the screen.
- One person thought the forms took longer than expected and one felt that the questions were too personal.
- Only one felt it was difficult to concentrate on the forms.
- Three found the computer equipment distracting and three were uncomfortable using a computer.
- No one felt that using the computer was embarrassing.

Results: Little Perceived Anxiety

- 96% of participants disagreed (21/50) or strongly disagreed (27/50) with the statement that “The questions made me anxious.”
- 92% agreed (23/50) or strongly agreed (23/50) that “Completing the questionnaire did not make me feel nervous.”

GTGCT1 Clinical Trial Summary

- Approximately 85% of the patients who were offered the opportunity to participate in the study agreed to participate.
- 100% of the participants were satisfied with the experience.

Conclusions and Comments (1)

- Web-based genetic services will assist primary care physicians in providing improved quality of care by:
 - Providing valid and up-to-date information;
 - Saving physician and staff time;
 - Reducing personnel expenses;
 - Providing quality assurance and control;
 - Saving patient time and expenses;

Conclusions and Comments (2)

- Web-based genetic services will assist primary care physicians in providing improved quality of care by:
 - Limiting genetic counseling or consultation to only the appropriate patients;
 - Permitting early detection and treatment;
 - Reducing cost of treatment;
 - Improving patient outcome.

Acknowledgements

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- To assist physicians and other healthcare providers in assessing whether a patient would benefit from genetic consultation, we have developed a series of web-based genetic screening questionnaires for use in primary care settings and obstetrics practices. The questionnaires provide a simple interactive format easily answered by the patients. The automated questionnaires then return an email message to the referring physician or healthcare provider and to the patient with a recommendation about the appropriateness of genetic consultation.
- To test the acceptance by patients and providers of web-based genetic screening, we conducted a pilot study in a primary care setting linked to a major medical center. The patients who use this clinic represent all socioeconomic levels and racial and ethnic groups. The pilot study included twenty-five obstetric patients and twenty-five patients seen for other reasons. After the patients submitted their genetic screening questionnaires, they also completed separate questionnaires evaluating their experience. All medical personnel completed analogous questionnaires evaluating their experience with the overall process. The results of the study will be discussed.