



## **Collaborative Development of Chatbots as an Innovative Tool in the Delivery of Scalable Genomic Counseling**

**Tara Schmidlen, M.S., LGC  
PAGC Annual Spring Meeting Philadelphia, PA May 4<sup>th</sup>, 2018**

# COI and Disclosures

- I am a paid employee of Geisinger, a non-profit integrated health system that serves more than 3 million residents in Pennsylvania and in southern New Jersey.
- Geisinger pays Clear Genetics, Inc, a healthcare technology company based in San Francisco, CA to develop chatbots.
- Geisinger staff members work with Clear Genetics staff members to collaboratively develop chatbots for use with patients enrolled in our MyCode<sup>®</sup> Community Health Initiative.
- MyCode<sup>®</sup> is funded by Regeneron Pharmaceuticals
- I am not paid by Clear Genetics. (Occasionally they do re-tweet me)

# We've got a problem...

Medscape

Wednesday, April 25, 2018

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News > Medscape Medical News > Conference News > 10th Future of Genomic Medicine (FOGM) Conference

## Shortage of Genetic Counselors in Face of Growing Need

Damian McNamara

March 13, 2017

LA JOLLA, California — Expansion of gen of medicine could help alleviate a growin shortage of genetic counseling professio of patients seeking interpretation of test i medicine.



MENTAL HEALTH & SELF-CARE

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## Genetic Counselor Shortages Mean Long Wait for BRCA Tests

The Scoop

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## Counselor Shortage Threatens Genome-based Diagnostics

By Meredith Salisbury | April 24, 2018, 2:35 PM | *Techonomy Exclusive*

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AUTHOR

Todd Bookman

NPR Shots

Published on Apr 18, 2016

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April 18, 2016 · 4:30 AM ET

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## More People Seek Genetic Testing, But There Aren't Enough Counselors

Projecting the Supply and Demand for Certified Genetic Counselors: a Workforce Study

Authors

Authors and affiliations

Jennifer M. Hoskovec, R. L. Bennett, M. E. Carey, J. E. DaVanzo, M. Dougherty, S. E. Hahn, B. S. LeRoy, S. O'Neal, J. G. Richardson, C. A. Wicklund

HEALTH IT, CONVERGENCE, DIAGNOSTICS

## Can telehealth solve America's genetic counselor shortage?

By JULIET PRESTON

Post a comment / May 25, 2017 at 7:39 AM

36

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## Angelina Jolie Disclosure Led to Shortage of Genetic Counselors

# Collaboration

"It is the long history of humankind that those who learned to **collaborate** and improvise most effectively have prevailed." – *Charles Darwin*

## Drives



"Alright, stop.  
**Collaborate**  
and listen." –  
*Vanilla Ice*

## Innovation

"Necessity is the mother of **innovation**"  
-Abraham Lincoln? Mark Twain? Steve Jobs?

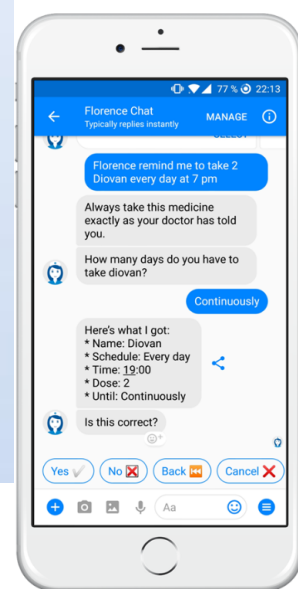
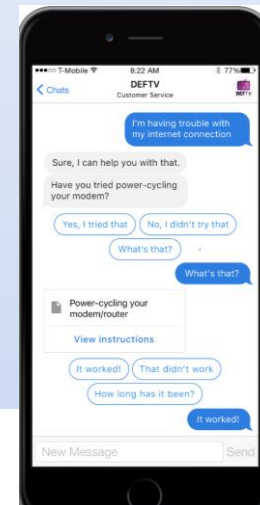
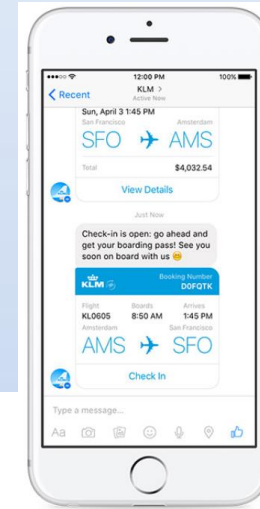
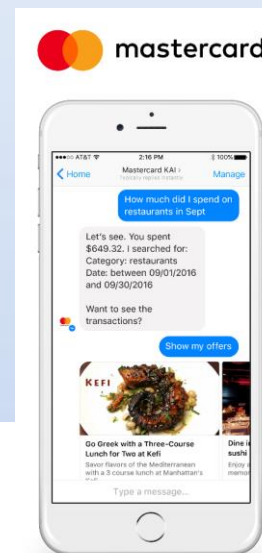
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# Innovations in Genetic Counseling

- Alternative Service Delivery Models
  - Phone counseling
  - Telemedicine
  - Group counseling
  - Web portals, online educational materials
  - Videos for pre-test education
  - Post-test only genetic counseling
  - Training other providers to provide basic counseling
  - Genetic counseling assistants
  - Chatbots!

# What is a chatbot?

- Chatbots are a technology-based simulated conversation tool used in scaling communications.
- Chatbots can:
  - Answer simple questions
  - Increase and maintain consumer engagement
  - Promote products and services
  - Provide convenient, easy access between consumers and service providers
- Chatbots are used in many settings
  - Banking and insurance industry
  - Retail and service
  - Travel-airlines and hotels
  - Health care providers





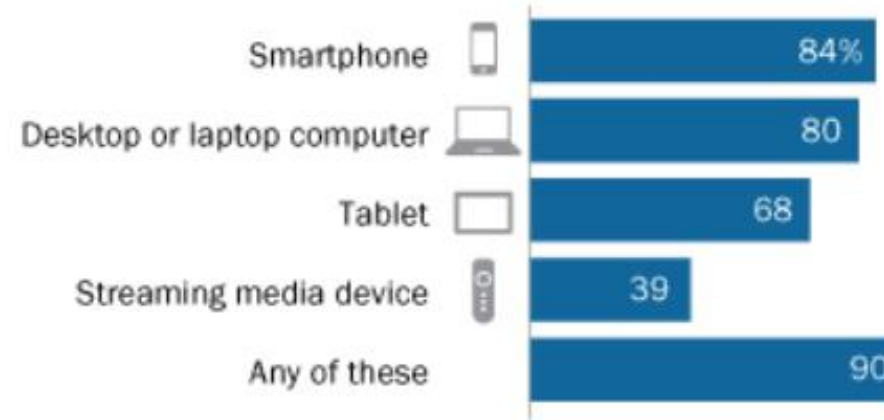
# Why Chatbots?

- Deploy by link, no app needed
- Phones, tablets, desktop PCs
- Personalized to the patient
- Back end analytics allow for seeing what, when and how patients interact with the bots
- EPIC integration/interfacing ability
  - Scheduling visits, sending kits
  - Chat transcript in EHR encounter
- Many potential use cases!
- Free up GCs for higher level, and billable patient care!

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## The typical American household contains multiple connected devices

% of U.S. adults who say their household contains a ...



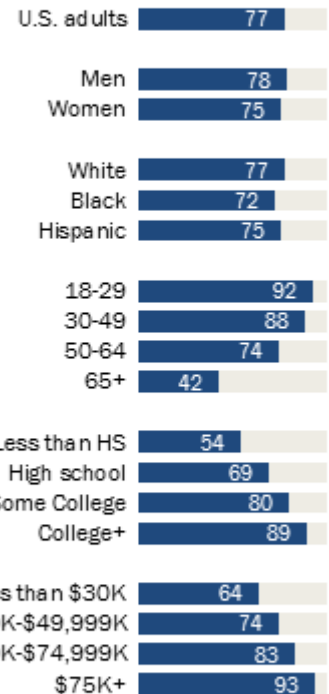
Note: Streaming media device refer to devices such as an Apple Chromecast or Amazon Fire TV.

Source: Survey conducted Sept. 29-Nov. 6, 2016.

PEW RESEARCH CENTER

## Roughly three-quarters of Americans own a smartphone

% of U.S. adults who say they own a smartphone



Note: Whites and blacks include only non-Hispanics.

Source: Survey conducted Sept. 29-Nov. 6, 2016.

PEW RESEARCH CENTER

# Collaboration



ClearGenetics

- Clear Genetics, Inc. is a healthcare technology company based in San Francisco, CA
- Clear Genetics combines the knowledge of experts in the field of genetics with artificial intelligence to create data-driven, HIPAA compliant chatbots that:



## Increase Access

Educate and triage at the point of care to open the funnel and allow more patients to benefit from genetic services.



## Improve Efficiency

Automate routine and time-consuming tasks, enabling genetics professionals to employ their expertise where it is needed most.



## Augment Care

Support patients across their genetic journey with personalized, interactive experiences that are convenient and easy to use.





**Goal:** Enroll and sequence 250,000 Geisinger patients into the MyCode<sup>®</sup> Community Health Initiative

**Research Objective:** Improve our ability to predict and prevent disease using genetic information

**Requirements:** Geisinger patient, blood samples and EHR access

**Returning Results for Actionable Genes:**

- Genes known to be associated with increased risks for disease (ACMGv2, heritable cancers, heritable heart disease)
- Pathogenic or likely pathogenic variants
- Diseases with established methods for prevention or early detection
- ~3.5-4% will receive a result

Geisinger





# MyCode<sup>®</sup> results returned

552 patient-participants have received results\*  
from the Genomic Screening and Counseling Program



For the latest results, see [geisinger.org/MyCode-results](https://geisinger.org/MyCode-results).

April 1, 2018

Risk condition 	Patients per risk condition 	Gene 	Patients per gene 
<u>CDC tier 1 conditions (click link)</u>			
<b>Hereditary breast and ovarian cancer</b> (early breast, ovarian, prostate and other cancers)	204	<b>BRCA1</b>	68
		<b>BRCA2</b>	136
<b>Familial hypercholesterolemia</b> (early heart attacks and strokes)	93	<b>APOB</b>	32
		<b>LDLR</b>	61
<b>Lynch syndrome</b> (early colon, uterine and other cancers)	56	<b>PMS2</b>	19
		<b>MSH6</b>	28
		<b>MSH2</b>	6
		<b>MLH1</b>	3

Totals

555



555

Top 3  
Conditions  
Reported

# Result Communication Workflow



- Patient-participant notified of results by phone



- Packet containing result report, educational materials, result sharing family letter is mailed



- Free genetic counseling is offered



- Patient-participants are connected to healthcare providers for screening and risk management



- 1 month follow up and 6 month follow up calls
  - Receive result packet? Gather family history? Meet with provider?  
Share results with relatives? Initiate screening/management?

# Chatbots for Scaling Genomic Counseling

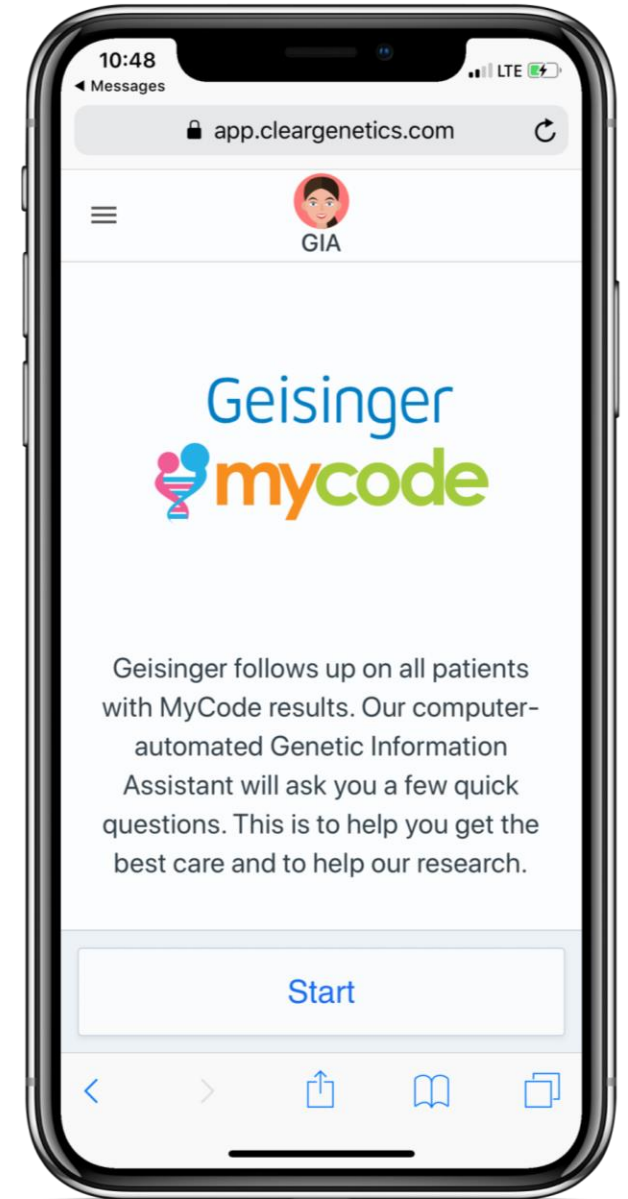
Introducing:



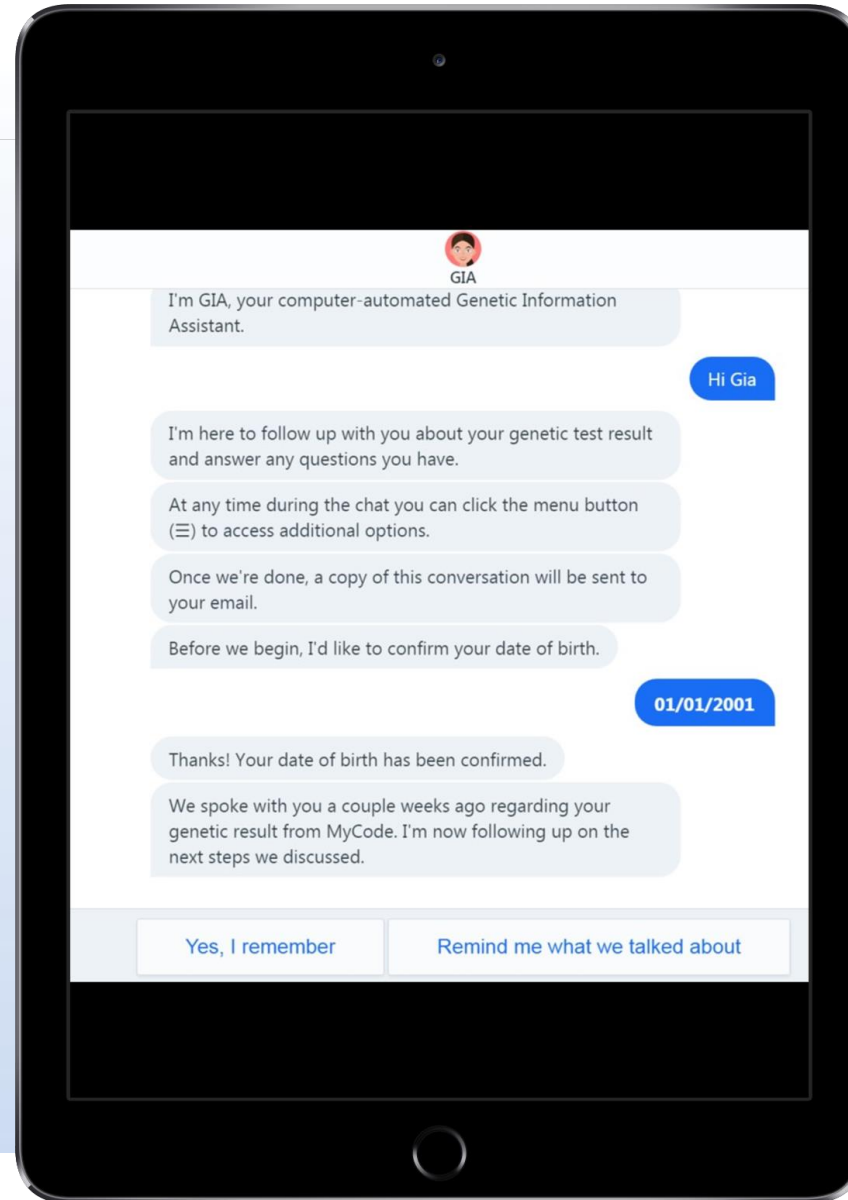
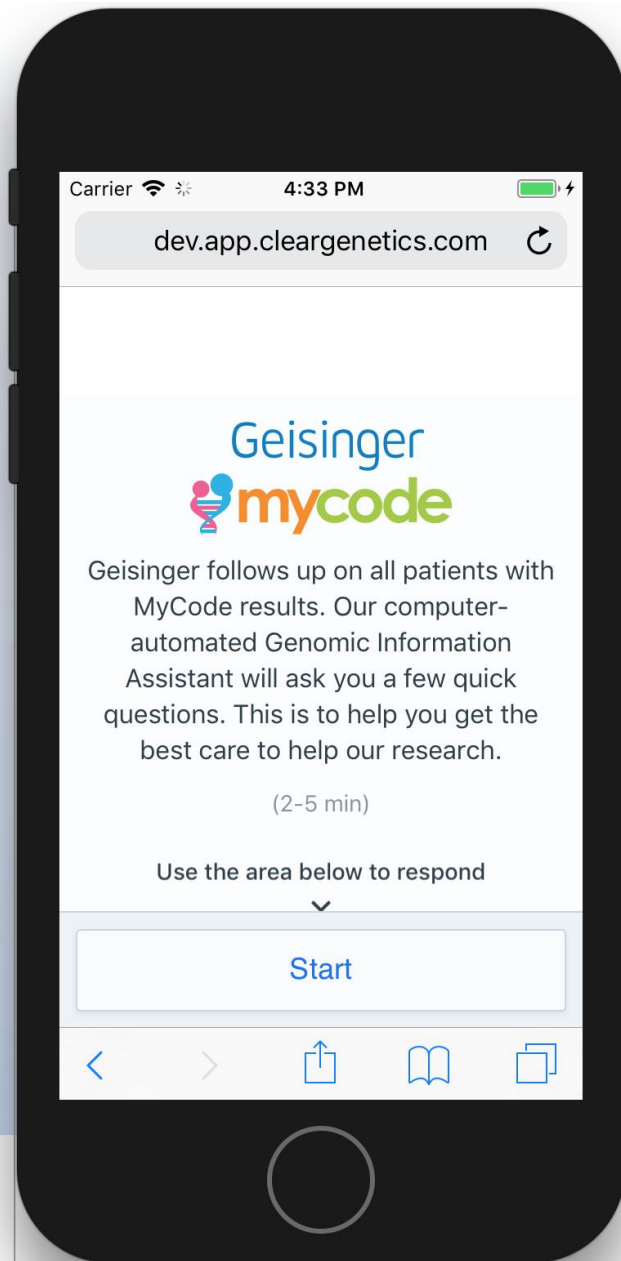
**GIA**


**Genetic Information Assistant**

Geisinger ClearGenetics



# Patient Follow-Up Chatbot



  
GIA

It's important that you speak with your provider to better understand the result and to determine next steps.

Do you want to schedule a **free appointment** with Geisinger's Clinical Genomics Department?

Yes

Sounds good! Please select the place and time that work best for you.

### Schedule Appointment


Location

Mountain View Care Center

Date/Time

Friday, March 2 2018, 1:45PM

Submit

  
GIA

You might remember that Geisinger developed the **MyCode Family Sharing Tool** to help you share your results with family members.

Your family members can also use this tool to schedule their follow up care with our team, or to inform additional family members you didn't reach out to yet.

That sounds great!

Wonderful.

I'll send you over to the **MyCode Family Sharing Tool** at the end of our chat.

Ok!

But before I do that, I want to make sure that you have all the information you need.

Do you have any additional questions?

Please type your question

Submit None



## Family Sharing Tool



Hi! I'm Gia, your Genetic Information Assistant.

Your genetic counselor probably told you that it's very important to share genetic results with your family members. I'm here to help you do that.

Share Now

## Who should I share with?



It's most important to share with your **first degree relatives** since they are at the highest risk - biological children, siblings and parents.

It's also a good idea to share with your **second degree relatives** - biological aunts, uncles, nieces, nephews, grandchildren, grandparents and half siblings.

Share Now



### Family Sharing Tool

This tool allows you to share a link to a chat with Gia, our Genetic Information Assistant. She will help your family members understand your genetic result, what it could mean for them, and how to get tested themselves.

Please choose how you would like to share that link below.  
(You can come back to this tool if you want to share in multiple ways).



I give my permission to share details of my genetic results with the recipient(s) of my Email, SMS, Facebook message or shared link, in accordance with these [HIPAA releases](#)



Send by Email



Send by SMS



Send by Messenger



Search



Guy



Home

2:04



Cancel My Genetic Testing Results Send

To:

Cc/Bcc:

Subject: My Genetic Testing Results

I recently had genetic testing and learned that I have a gene change that may affect my health. Because we are blood relatives and share genetics, this result could impact you too. Please click the link below to learn more about what this means and what you can do.

<https://app.cleargenetics.com/invite/x5a8d430dbe7a5/share>

### Send a Message

To Enter friends

Message

### Genetic Information Sharing Tool

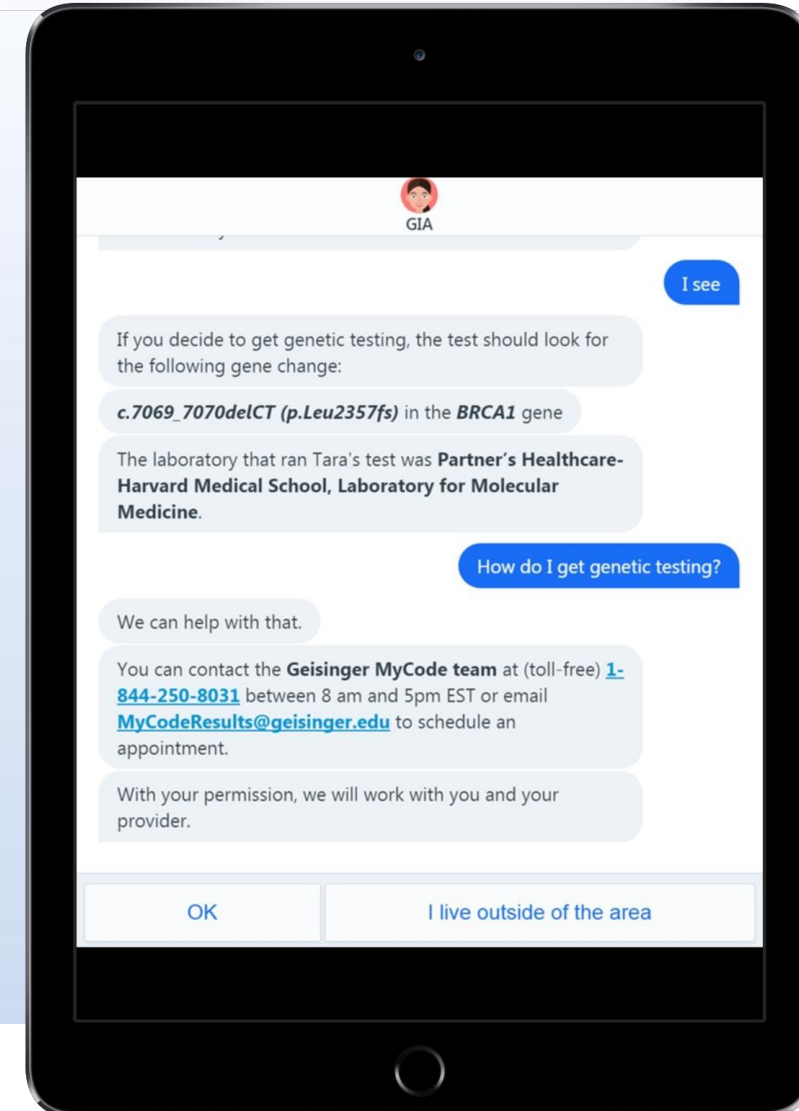
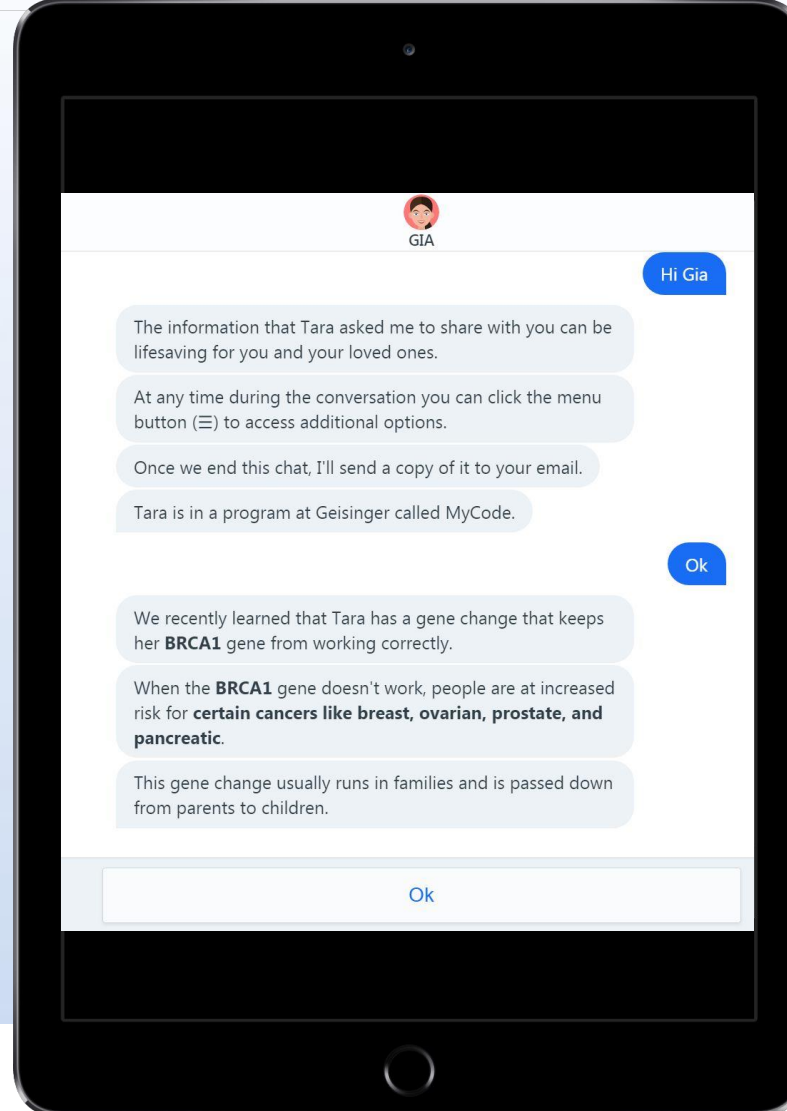
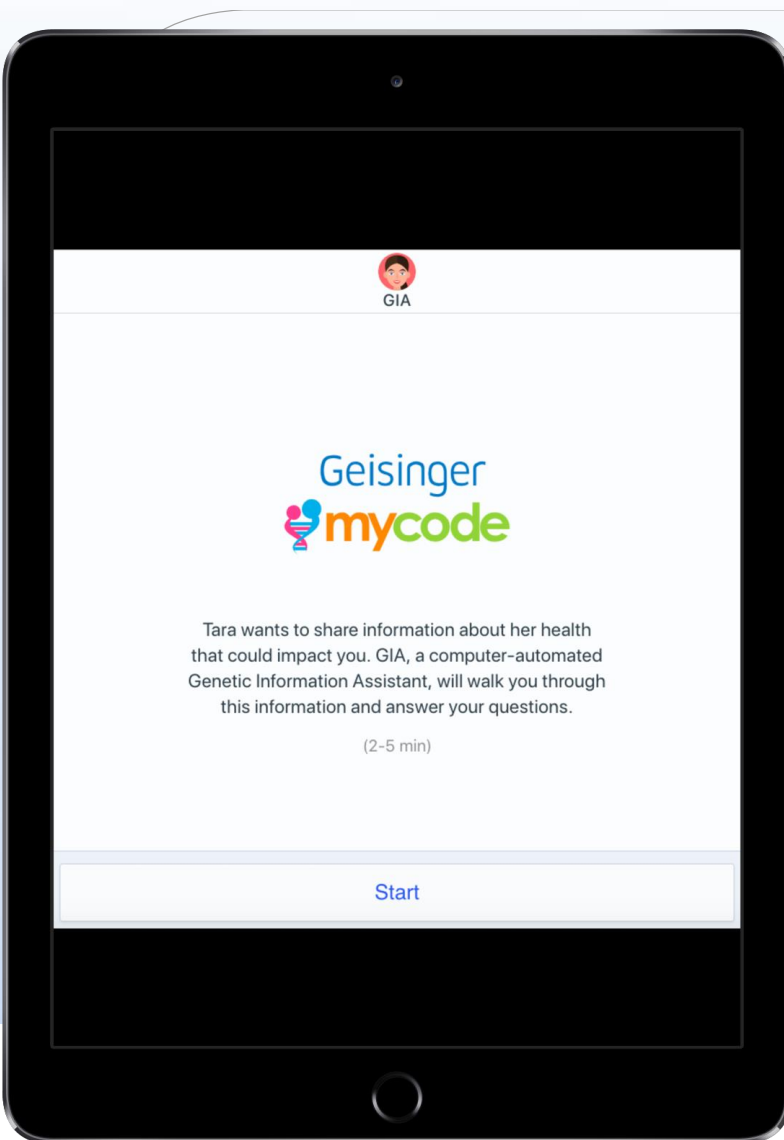
Family members share genetics. So it only makes sense that we should also share information about our genetics. Let's start the domino effect of improved care based on genetic information.

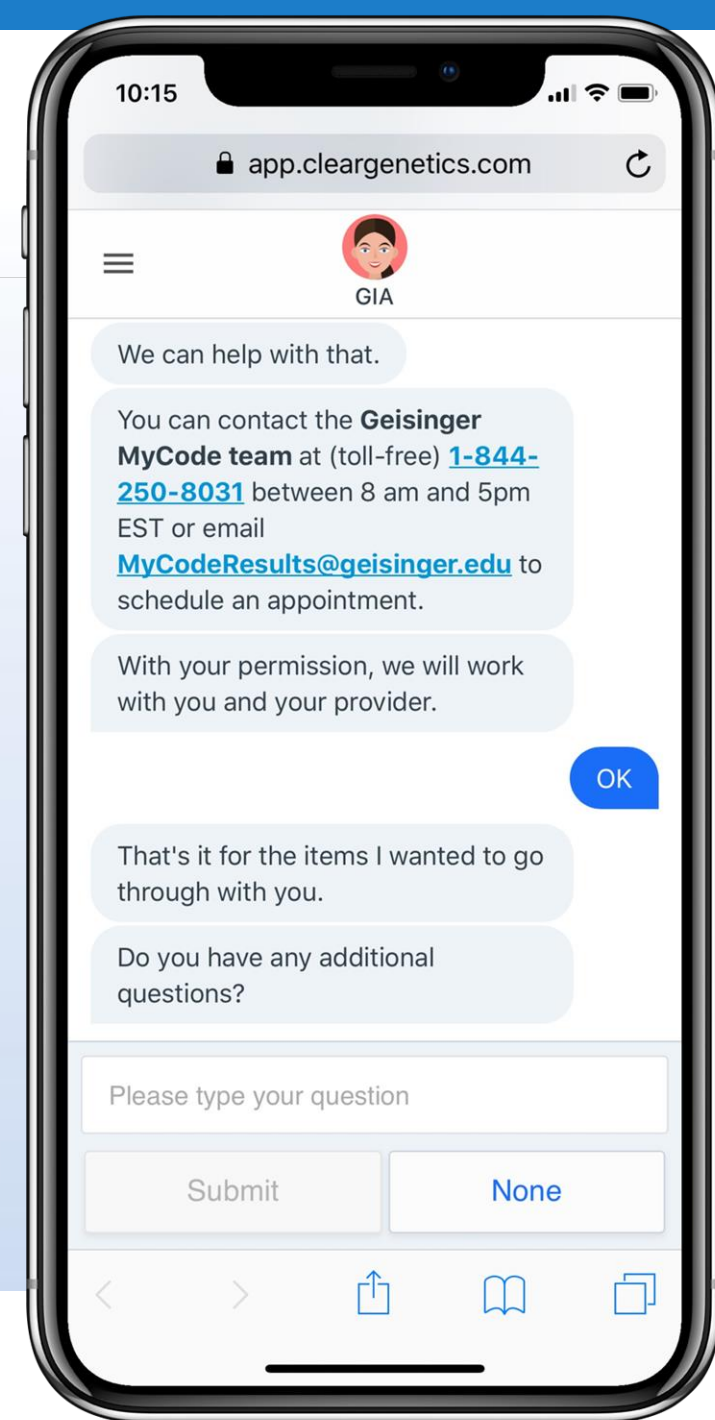
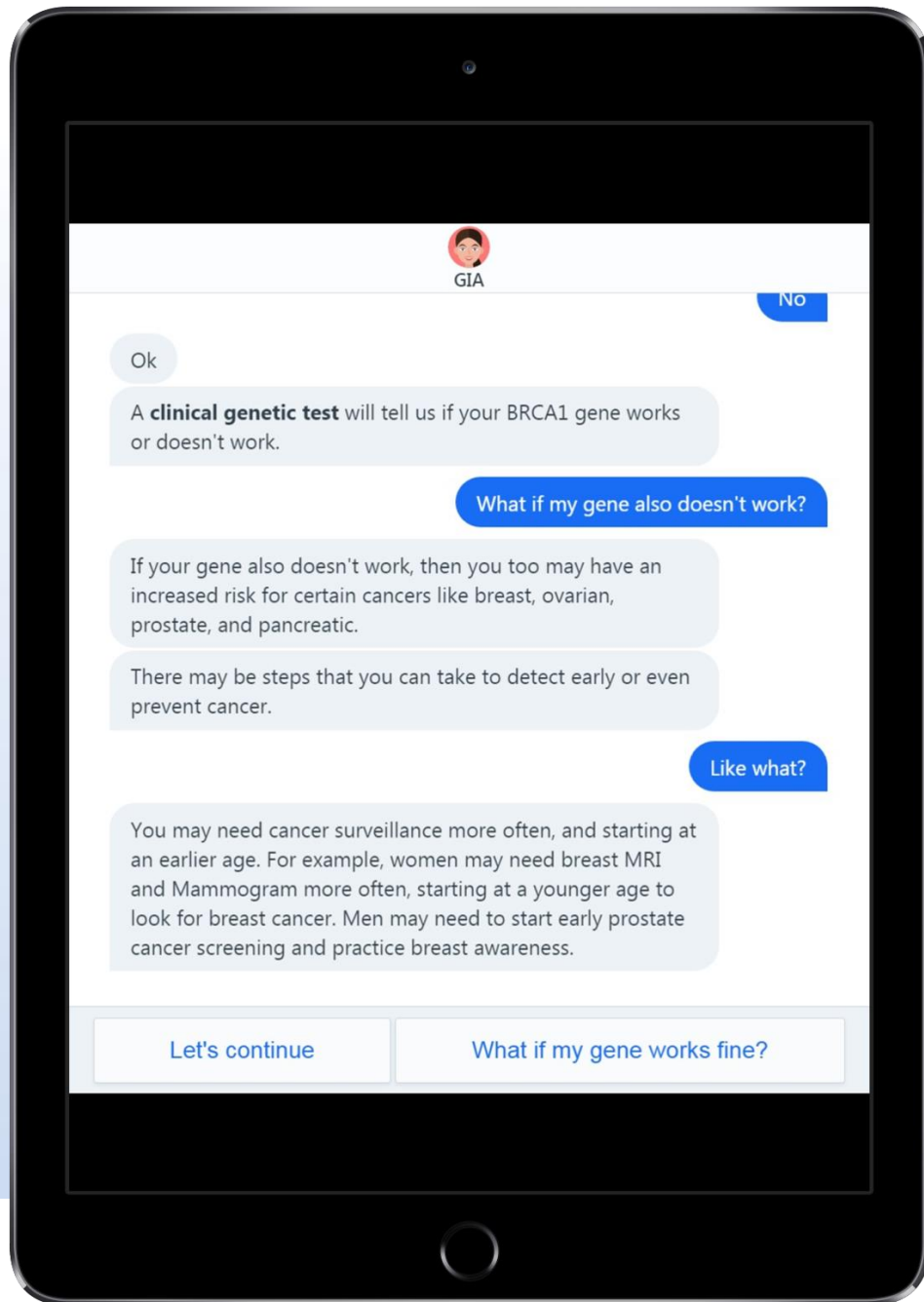
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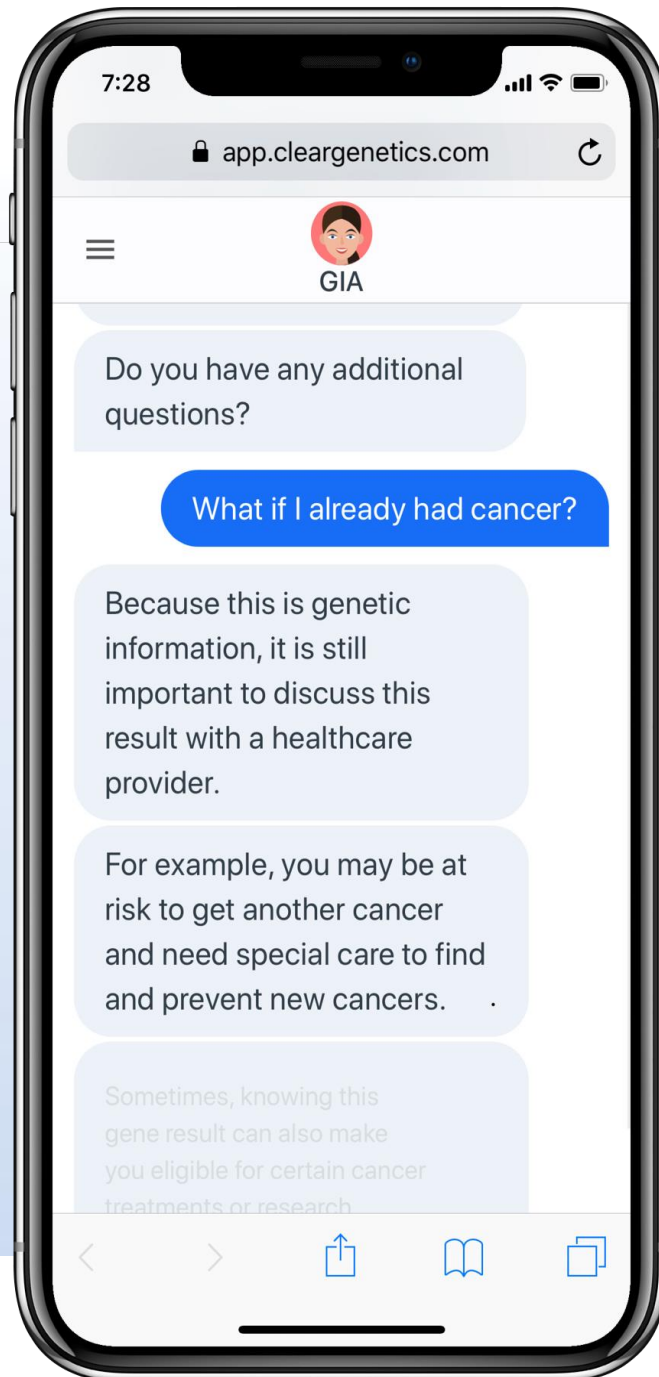
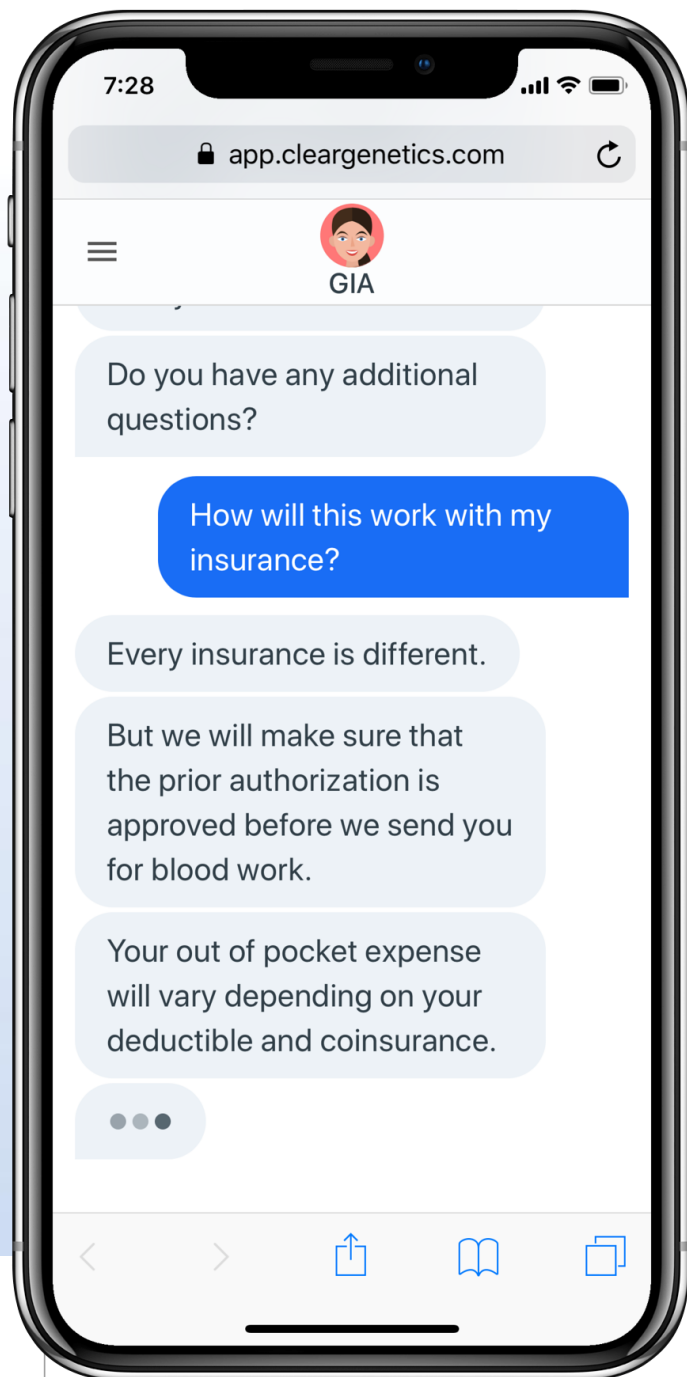
Send

Cancel

# Cascade Chatbot







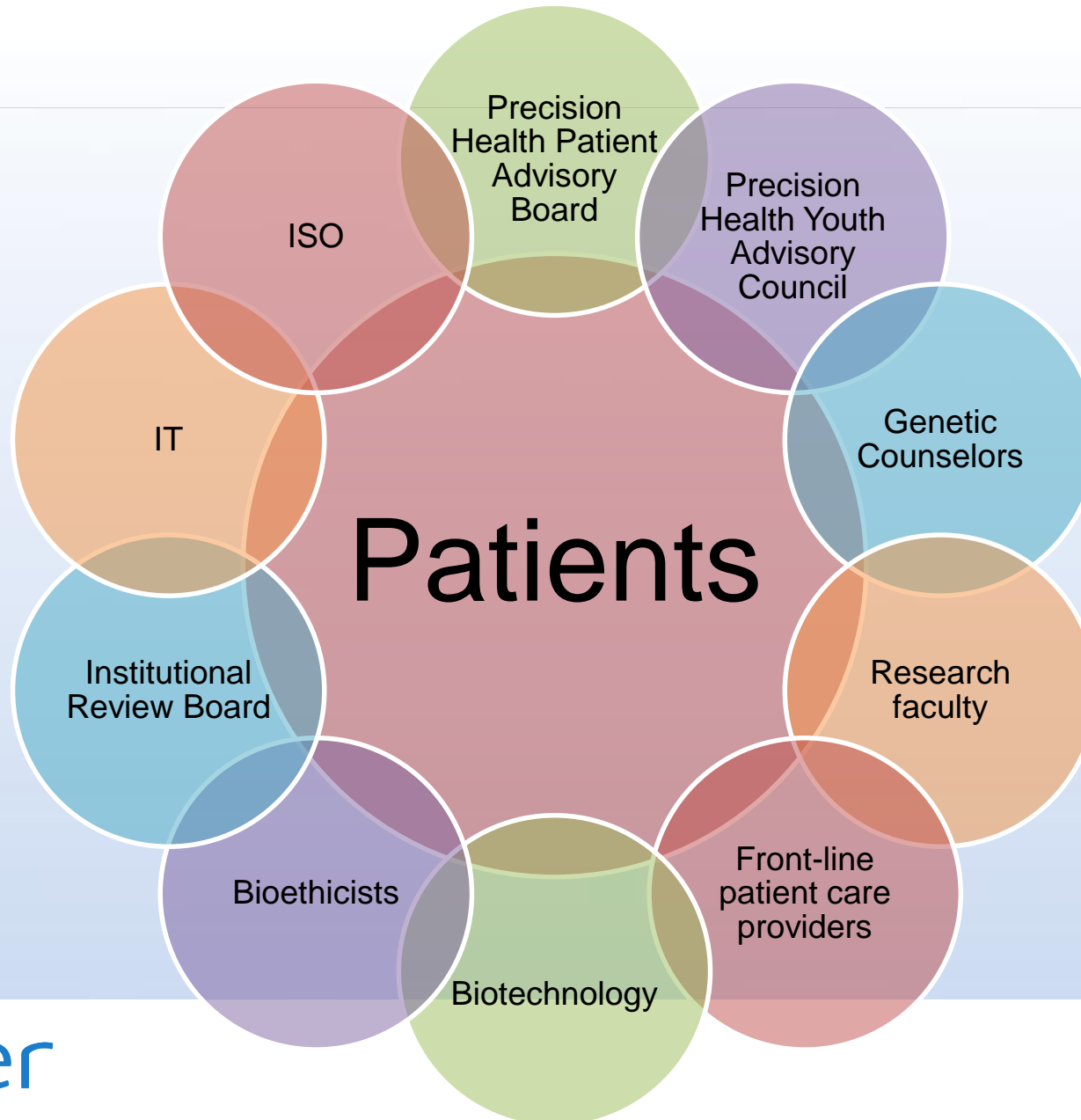


# Collaborative and Iterative Development

- Clear Genetics team came to Geisinger for observation visits
  - RAs making result disclosure and 1 month follow up calls
  - GCs making 6 month follow-up calls
  - GCs and patients in a cascade genetic counseling visit
- Geisinger provided Clear with phone scripts and cascade testing letters
- Clear developed an alpha version of the follow-up and cascade chatbots
- Bot links were circulated and feedback was collected by email and word documents from Geisinger team members
- Suggestions and action items were tracked on a spreadsheet
- Zoom calls for “face-to-face” working meetings
- Emails. SO. MANY. EMAILS.



# Collaboration Drives Innovation



# Pilot Testing

- Initial feedback on high-fidelity prototypes collected via email
- Pilot testing conducted via usertesting.com
- Verbal response to questions assessing functionality, acceptability and understanding were collected
- Participants were prompted with open-ended questions on:
  - Purpose of the chat
  - Intended recipient
  - Chat partner (person/computer)
  - Personality
  - Clarity and intuitiveness
  - Preferences
  - Suggested improvements

 8 women

 4 men

 Age range 37-78

 Income <\$40K=8, \$40K-100K=4

# Pilot Results

- Participants describing correct purpose and target audience: 12 participants (n=8 cascade, n=4 follow-up)
- Participants rating chatbots “easy and intuitive” to use: n=12
- Participants rating the chatbot as a positive interaction: n=12
- Most common descriptors of chatbot personality: “friendly” (n=4)  
“professional” (n=4)

# Pilot Results

- Participants feelings about using the cascade chatbot to share health information with family members:
  - 4 used the word “comfortable”
  - *“This sort of news is better delivered by humans.”*
  - *“Where did (relative) give them my personal information? Trust is major for divulging medical history. I want to be sure I'm talking to someone legitimate.”*
  - *“With family it’s sometimes very emotional. With this (tool) you immediately get right information from the experts. You have a nice knowledge base and potentially calm nerves.”*

# Pilot Results

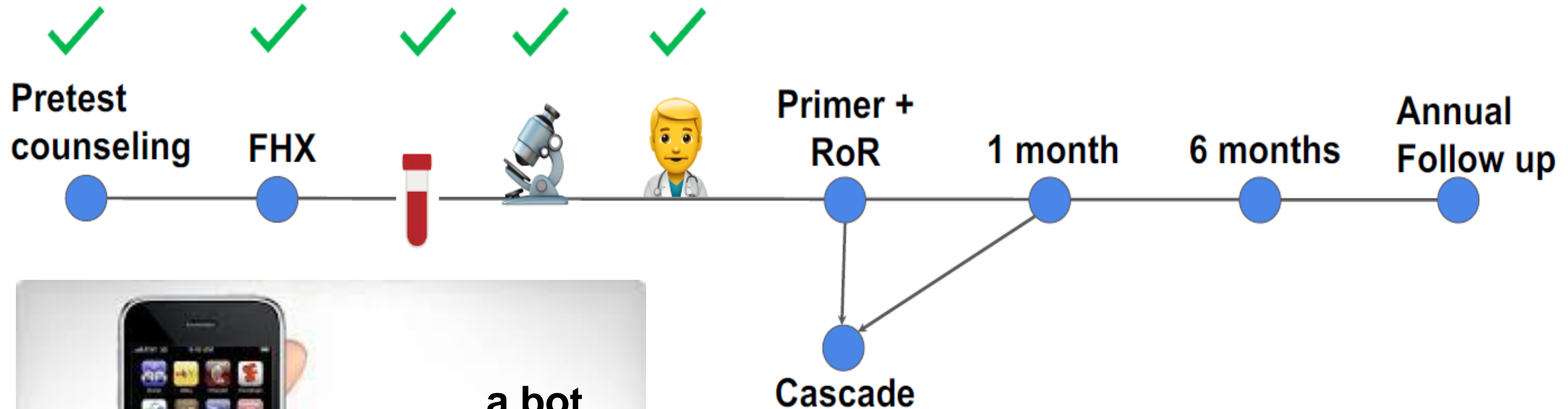
- Suggested improvements:
  - Introduce chatbots by email
  - Add more encouragement to see a doctor
  - Use less jargon
  - Add links to information on genes
  - Add links to information on cancer risks without a variant.
- Results suggest that the cascade and follow-up chatbots *might* be an acceptable, user-friendly mechanism to perform common tasks needed in the delivery of scalable genomic counseling
- Further testing is needed and is currently underway

# Ongoing Chatbot User Testing

- Patient Focus Groups (n=60-90)
  - Demographics
  - 3 representative areas of patient population
- SurveyMonkey Surveys (n=300) / Mechanical Turk
  - Demographics
  - Comprehension
- Validately User Testing Application (n=60)
  - Demographics
  - Audio capture of participants talking aloud in response to prompts
  - Video screen capture of participants navigating through the chatbots
  - Comprehension



# How can chatbots help scale genomic medicine?



# Closing Quote

“Are we necessary mediators or barriers?”

-Kaylene Ready, MS CGC    ACMG 2018 TED Talk

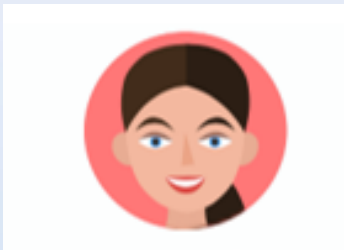


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# Acknowledgements

## Clear Genetics Team

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- GIA



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- Marc S. Williams, M.D.
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# Thank you!

Questions?  
Collaborations?

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