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

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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® Community Health Initiative.

MyCode® is funded by Regeneron Pharmaceuticals

I am not paid by Clear Genetics. (Occasionally they do re-tweet me)
We’ve got a problem…

Counselor Shortage Threatens Genome-based Diagnostics

LA JOLLA, California — Expansion of genomics could help alleviate a growing shortage of genetic counseling professions, a recently published study has found.

Can telehealth solve America’s genetic counselor shortage?

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?
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!

Geisinger
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® 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
### Top 3 Conditions Reported

<table>
<thead>
<tr>
<th>Risk condition</th>
<th>Patients per risk condition</th>
<th>Gene</th>
<th>Patients per gene</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hereditary breast and ovarian cancer</strong></td>
<td>204</td>
<td>BRCA1</td>
<td>68</td>
</tr>
<tr>
<td>(early breast, ovarian, prostate and other cancers)</td>
<td></td>
<td>BRCA2</td>
<td>136</td>
</tr>
<tr>
<td><strong>Familial hypercholesterolemia</strong></td>
<td>93</td>
<td>APOB</td>
<td>32</td>
</tr>
<tr>
<td>(early heart attacks and strokes)</td>
<td></td>
<td>LDLR</td>
<td>61</td>
</tr>
<tr>
<td><strong>Lynch syndrome</strong></td>
<td>56</td>
<td>PMS2</td>
<td>19</td>
</tr>
<tr>
<td>(early colon, uterine and other cancers)</td>
<td></td>
<td>MSH6</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td></td>
<td>MSH2</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>MLH1</td>
<td>3</td>
</tr>
</tbody>
</table>

**Totals** 555
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

Geisinger follows up on all patients with MyCode results. Our computer-automated Genomic Information Assistant will ask you a few quick questions. This is to help you get the best care to help our research.

(2-5 min)

Use the area below to respond

Start

Great! As you remember, we discussed three important next steps:

1. See a provider
2. Learn more about your family health history
3. Share results with family members

Were you able to schedule an appointment regarding this genetic result?

Yes, I already had my appointment
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?

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

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.

Wonderful.

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

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
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.

Who should I share with?

What will I be sharing?

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.

What will I be sharing?

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

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
Cascade Chatbot

Geisinger mycode

Tara wants to share information about her health with her family. GIA, a computer-automated Genetic Information Assistant, will walk you through this information and answer your questions.

(2-5 min)

Start

Geisinger

GIA

The information that Tara asked me to share with you can be lifesaving for you and your loved ones.

At any time during the conversation you can click the menu button on the chat screen to access additional options.

Once we end this chat, I'll send a copy of it to your email.

Tara is in a program at Geisinger called MyCode.

We recently learned that Tara has a gene change that keeps her BRCA1 gene from working correctly.

When the BRCA1 gene doesn't work, people are at increased risk for certain cancers like breast, ovarian, prostate, and pancreatic.

This gene change usually runs in families and is passed down from parents to children.

Ok

GIA

If you decide to get genetic testing, the test should look for the following gene change:

c.7069_7070delCT (p.Leu2377fs)

The laboratory that ran Tara's test was Partner's Healthcare-Harvard Medical School, Laboratory for Molecular Medicine.

We can help with that.

You can contact the Geisinger MyCode team at (toll-free) 1-844-250-8031 between 8 am and 5 pm EST or email MyCodeResults@geisinger.edu to schedule an appointment.

With your permission, we will work with you and your provider.

Ok

Ok

Ok

I live outside of the area
A clinical genetic test will tell us if your BRCA1 gene works or doesn’t work.

What if my gene also doesn’t work?

If your gene also doesn’t work, then you too may have an increased risk for certain cancers like breast, ovarian, prostate, and pancreatic.

There may be steps that you can take to detect early or even prevent cancer.

Like what?

You may need cancer surveillance more often, and starting at an earlier age. For example, women may need breast MRI and Mammogram more often, starting at a younger age to look for breast cancer. Men may need to start early prostate cancer screening and practice breast awareness.

Let’s continue  What if my gene works fine?
Do you have any additional questions?

How will this work with my insurance?

Every insurance is different.

But we will make sure that the prior authorization is approved before we send you for blood work.

Your out of pocket expense will vary depending on your deductible and coinsurance.

Do you have any additional questions?

What if I already had cancer?

Because this is genetic information, it is still important to discuss this result with a healthcare provider.

For example, you may be at risk to get another cancer and need special care to find and prevent new cancers.

Sometimes, knowing this gene result can also make you eligible for certain cancer treatments or research.

What can I help you answer?

What about my mom

I want to make sure I’m answering the right question. Are you asking *is my family at risk?*

Yes

If you find out that you do have the gene change, it means that your close blood relatives (parents, children, siblings) have a 50% chance of having this DNA change.
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

- Patients
- Precision Health Patient Advisory Board
- Precision Health Youth Advisory Council
- Genetic Counselors
- Research faculty
- Front-line patient care providers
- Biotechnology
- Bioethicists
- Institutional Review Board
- IT
- ISO

Geisinger
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

Demographics:
- 8 women
- 4 men
- Age range: 37-78
- Income: $40K-80K=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?

- Pretest counseling
- FHX
- Primer + RoR
- 1 month
- 6 months
- Annual Follow up

There's an App For That
Closing Quote

“Are we necessary mediators or barriers?”

-Kaylene Ready, MS CGC   ACMG 2018 TED Talk
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Questions?
Collaborations?

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