

Executive Summary

This focus group was created to assist Professor Carrie Heeter with developing a science grant funded project called **DNA Communities**.

The participants of the focus group are **enrolled at Michigan State University in a graduate course** and are members in specific final project teams. There were four females and three males. Because the course focuses on Design Research, they were recruited as a requirement for the course.

Findings reveal that participants are interested in content that is **personally relevant, meaningful, and has some significant impact on their life**. Specifically, content related to genetic information and fatal diseases generated the **most interest** out of all participants because obtaining this knowledge could allow them to “change [their] lifestyles to significantly change risk” and seek **early detection and subsequent prevention**. Several participants cited that they “would want to know for trials and treatment” and prevention “that you can do to lower the risk and stay head of it” by getting “checked more often.” Conversely, some participants expressed concern that knowing how a genome can impact their lives would “**ruin quality of life**” and “**it might be better just to live.**” Most of the participants viewed the social issues involving patented genomes, a child’s right to genetic privacy, and denying life-extending medicine for short life expectancy as **unethical** with the second scenario gaining the most support. Majority of the participants also **expressed interest** in voting on DNA Communities, viewing how others voted, and seeing who voted. Specifically, participants wanted to see opinions with **reasoning** from **diverse** individuals on a variety of genetic issues; other participants advocated for having **experts** and professional insight. After revealing preliminary graphics for the site, many participants expressed **confusion and frustration** and suggested **simplifying the designs, using color coding, and clearly stating a call to action**.

Based on the participants’ feedback, it is recommended that the content for DNA Communities be **personally relevant, meaningful, and significantly impactful** in the sense that users can **adjust their lifestyles and seek early detection and prevention**. Content should **avoid** raising awareness about **diseases or conditions** that have **no form of intervention** as many participants cited that this knowledge will ruin the user’s **quality of life**. In addition, designers must develop a more focused target audience and commit to a persuasive or informative stance with clear purpose because several participants were confused on the call to action. Some believed the site was a great “**non-partisan**” site while others thought it had potential to **impact policy** if more **persuasive elements** were introduced. It is also recommended that the forum include a variety of diverse opinions and reasoning which features genetics experts. Finally, it is recommended that the **interface** use more **color coding and simpler navigation with distinguishable tabs**.

Methods

The purpose of this focus group is to provide Professor Carrie Heeter with meaningful insight into target audiences and possible forms of interactivity for a science grant funded project titled DNA Communities.

Participants of this focus group were chosen through a convenience sample. The focus group participants were chosen based on their **enrollment in a specific Michigan State University graduate course, Design Research**, and membership in specific final project groups, **Team iHOP and Team Awesome**, which were segmented based on interests in **social concierges and sports respectively**. No other form of advertisement or recruitment for additional participants was conducted. For this reason, the sampling was not representative of any population or group except for the narrow interests contained within the two final project groups.

Because the purpose of this focus group was to identify potential target audiences for the DNA Communities project and simultaneously provide the participants with experience conducting a Focus Group session, the researchers were not specified with a desired audience other than the individuals available during the Focus Group time. Rather, the Focus Group consisted of **graduate students proficient in digital media and interested in some form of telecommunications** and also **possessed some basic knowledge and curiosity of biological functions related to genetics**.

Seven individuals, three male and four female, participated in the focus group on February 7, 2011 as part of a class assignment. The interview process consisted of several questions which asked for the participants to determine their interest in learning about different genetic risks and participation in an online community. No compensation was provided for participation. Because the researchers had difficulty seeing and hearing the participants, a follow-up online survey with multiple choice and short answer responses was conducted with almost every member responding by February 14, 2011.

Table 1: Participant Demographics

Pseudonym	Gender	Estimated Age	Ethnicity	Personality
Genius George	Male	Early 30's	Caucasian	Intellectual
Sincere Shamu	Female	Early 20's	Caucasian	Friendly
Shy Sophie	Female	Mid 30's	Asian	Shy
Jovial James	Male	Early 20's	Caucasian	Jovial
Honest Hector	Male	Early 30's	African-American	Opinionated
Confident Corey	Female	Late 20's	African-American	Confident
Exuberant Xena	Female	Late 20's	African-American	Bold

Findings

I. Opening

Existing DNA Knowledge – “What percent of DNA is identical in all humans?”

Table 2: Participant Guesses on Genetics Question

Pseudonym	Guess	Answer
Genius George	99.9%	Correct
Sincere Shamu	5%	Wrong
Shy Sophie	99.5%	Inaccurate
Jovial James	98.6%	Inaccurate
Honest Hector	97.63%	Inaccurate
Confident Corey	95%	Inaccurate
Exuberant Xena	3%	Wrong

Overall

While this question served as an icebreaker, it also revealed a basic understanding of current genetics education for graduate students in telecommunications-related fields. **In general, the male students answered much more accurately than the female students.**

Details

Sincere Shamu said, “I guess, I’m going to go the opposite and say 5% ‘cause I don’t know.” This was followed by Jovial James who said, “I guess 98.6%.” Of the remaining participants, there was quite a bit of laughter and fun in guessing numbers.

Insights

Although fun, this question revealed that graduate students in telecommunications haven’t really thought about genetics concepts or the similarities shared between people. Interestingly enough, two of the female participants, Sincere Shamu and Exuberant Xena, guessed answers completely wrong while Shy Sophie guessed the 2nd closest answer. This isn’t conclusive enough to determine whether males have more education related to genetics but is interesting to note. Of all the participants, only Genius George seemed confident in the right answer. This particular question seemed to be very engaging and created a lot of interest in learning further about human DNA and the connections between people. **Design considerations with DNA Communities should reflect similar scenarios that are fun and generate discussion.**

II. Suggested Content for DNA Communities

Participant Interest in Personal Genetic Risks

Table 3: Summary of Participant Interest in Personal Genetic Risks

Pseudonym	Alcohol	Alzheimer's Disease	Bitter Tastes	Caffeine Processor	Ancestry	Breast/Prostrate Cancer	Malaria
Genius George	Yes	No	No	No	Yes	Yes	No
Sincere Shamu	Yes	No	Maybe	Yes	Yes	Yes	No
Shy Sophie	Yes	Yes	No	Yes	Yes	Yes	No
Jovial James	No	Yes	Yes	Yes	Yes	Yes	No
Honest Hector	No	Yes	No	No	Yes	Maybe	Maybe
Confident Corey	NR	Yes	NR	NR	Yes	Yes	No
Exuberant Xena	No	Yes	No	No	Yes	Yes	No

Summary

The above graphic presents a summary of the positions that each participant took on a variety of potential content for DNA Communities. From the discussions below (which contains more specific discussions relevant to each subject), several themes emerged. Many of the participants expressed more **favorable interest on content related to serious or fatal diseases and specifically advocated for the ability to gain insight into early detection and prevention of these ailments.** Without any means of prevention, a few participants expressed concern that providing this content could **ruin the quality of their lives.** The only category not fitting this description was ancestry which was advocated by the participants as a means of satisfying curiosity.

Participant Interest in Personal Genetic Risks to Susceptibility to Alcohol

Table 4: Participant's Interest in Genetic Risks to Susceptibility to Alcohol

Pseudonym	Susceptibility to Alcohol	Comments
Genius George	Yes	"Easier to plan and deal with the problem."
Sincere Shamu	Yes	"If I were more susceptible, I wouldn't ever drink."
Shy Sophie	Yes	"If I don't have drinking experience, I'd like to know."
Jovial James	No	"You can figure it out anyway..."
Honest Hector	No	"I'm not a drinker, so it wouldn't matter."
Confident Corey	NR	No response provided.
Exuberant Xena	No	"No, because I am not a drinker."

Overall

Surprisingly **three out of seven participants identified themselves as non-drinkers** and subsequently indicated that knowing about their susceptibility to alcoholism was irrelevant. Of those that do drink, two out of the seven participants indicated that knowing about their susceptibility to alcohol would allow for them to “plan and deal with the problem.”

Details

Exuberant Xena, Shy Sofie, and Honest Hector all identified themselves as non-drinkers. Of those three, Exuberant Xena was the only one to express her disinterest in learning about her genetic susceptibility to alcohol. Conversely, Shy Sofie said that she would like to know and Honest Hector expressed ambivalence by saying “I’m not a drinker, so it wouldn’t matter to me.”

Jovial James did not express a conclusive answer but offered his disinterest by saying, “You can figure it out anyway...I don’t know if it would be harder to deal with.”

Of those participants interested in learning more, Genius George said, “I would also like to know – it’s easier to plan and deal with the problem.” Sincere Shamu reinforced this point and expanded further by saying, “**Yes, I would want to know because if I were more susceptible, I wouldn’t ever drink.**”

Insights

The most surprising revelation emerging from this discussion was the fact that **almost half of the participants identified themselves as non-drinkers**. Considering a common stereotype that many college students and adults drink at least occasionally, the participants’ responses illustrate the importance of truly understanding the target audience.

Although four of the participants weren’t interested in knowing about their genetic susceptibility to alcoholism, two participants who have presumably consumed alcohol before, Genius George and Sincere Shamu, indicated they would “plan and deal with the problem” and “wouldn’t ever drink” respectively. This highlights an important discovery in choosing content for the DNA Communities project at least among these participants in the sense that **irrelevant content was quickly dismissed while information relevant to specific individuals demonstrated the capability to completely alter one’s lifestyle**. If the objective of the project is to educate and shape the target audience’s lifestyle, content must be relevant to the user as **purely educating someone isn’t enough to capture attention**.

Participant Interest in Personal Genetic Risks to Alzheimer’s Disease

Table 5: Participant’s Interest in Genetic Risks to Alzheimer’s Disease

Pseudonym	Alzheimer’s Disease	Comments
Genius George	No	“There’s not a lot you can do to avoid it... there’s some mental exercise you can do, but that’s it.”
Sincere Shamu	No	“I would not want to know...it would ruin my quality of life.”
Shy Sophie	Yes	“Definitely I want to. Then I can tell my family members and friends to make preparation.”
Jovial James	Yes	“I would want to know for trials and treatment...the earlier the better.”
Honest Hector	Yes	“I would want to know so I could alert other people when I start acting crazy in the future.”
Confident Corey	Yes	“I would so I could start writing stuff down and begin to take pictures.”
Exuberant Xena	Yes	“I would like to be prepared.”

Overall

Five out of seven participants indicated they would be interested in knowing their genetic risks to Alzheimer’s Disease and specifically cited **preparation as a primary factor** in their decision to know more. Two of these five participants, a female and a male, referenced wanting to **tell “family members and friends to make preparation”** when they “start acting crazy in the future” respectively.

Of the two participants who did not want to know, one justified the reasoning as “there’s not a lot you can do to avoid it” and another explained that “it would ruin my quality of life.” Both participants seemed to feel the disease was unpreventable and acted somewhat discouraged by the thought of knowing one’s fate.

Details

Majority of the participants expressed interest in knowing their genetic risks to Alzheimer’s Disease because it would allow for early preparation. **The group seemed very engaged because the disease could impact everyone.**

Exuberant Xena stated, “I would like to be prepared” while Confident Corey took this statement one step further by offering insight into how to prepare by **“start writing stuff down and begin to take pictures.”** Along the same lines, Jovial James said he would **“want to know for trials and treatment”** because **“the earlier the better.”**

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The other two participants cited preparing family and friends as a primary reason for wanting to know. Honest Hector stated, "I would want to know so I could alert other people when I start acting crazy in the future" and Shy Sofie enthusiastically replied, "Definitely I want to. Then I can tell my family members and friends to make preparation."

Of the two participants who did not want to know, they seemed to perceive Alzheimer's Disease as unpreventable. Replying somewhat frustrated, Genius George ominously explained, "There's not a lot you can do to avoid it" other than "some mental exercise you can do, but that's it." Sincere Shamu hesitantly expressed her fear that knowing "would ruin my quality of life."

Insights

A majority of the participants expressed interest in learning about their **susceptibility to Alzheimer's Disease because it allowed them to prepare themselves by looking "for trials and treatment...earlier," "start writing stuff down and begin to take pictures," and telling "family members and friends to make preparation."** By obtaining knowledge of their genetic risks, they recognize that it won't prevent the disease but rather ease the burden on their loved ones. With this in mind, it is **strongly recommended that the DNA Communities project focus on content which advocates for risks related to early detection and prevention and family support.**

The two participants who expressed disinterest in learning about Alzheimer's Disease, Genius George and Sincere Shamu, revealed that knowing about risks when **"there's not a lot you can do to avoid it" will simply "ruin my quality of life."** From these insights, it becomes more apparent that DNA Communities shouldn't include content that is simply raising awareness without any tangible call to action, such as prevention, for the user. **If content that only educates is included, the users become frustrated and alarmed; moreover, it can ruin their quality of lives because they will continuously dwell on a fate that may or may not come.**

Participant Interest Genetic Ability to Perceive Bitter Tastes

Table 6: Participant’s Interest in Genetic Ability to Perceive Bitter Tastes

Pseudonym	Ability to Perceive Bitter Tastes	Comments
Genius George	No	“I’m not sure if it matters...it’s pretty insignificant.”
Sincere Shamu	Maybe	“I’m not sure I would really want to know. I would always be wondering what other people were tasting rather than enjoying my food with my own sense of taste.”
Shy Sophie	No	“No, it will destroy my appetite.”
Jovial James	Yes	“I would probably just for curiosity’s sake.”
Honest Hector	No	“No.”
Confident Corey	NR	No response provided.
Exuberant Xena	No	“No, I don’t care too much about bitter tastes.”

Overall

Four of the participants were not interested in knowing their ability to perceive bitter taste with many of them citing it as **“pretty insignificant”** or destructive toward their appetites.

Only one participant expressed interest in knowing for “curiosity’s sake” and another seemed partially interested but expressed concern that it would wreck her ability to enjoy her own food with her “own sense of taste.”

Of the participants, two females cited that it would ruin their appetites, one male expressed interest, and one male and one female stated that it seemed insignificant.

Details

Many of the participants thought knowing about the ability to detect bitter taste was pretty insignificant. Genius George stated in a hostile tone, “I’m not sure if it matters...it’s pretty insignificant” and Exuberant Xena reinforced this message with, “No, I don’t care too much about bitter tastes.” In addition, Honest Hector bluntly replied, “No.”

Two of the female participants expressed concern that knowing about their ability to perceive bitter tastes could ruin their appetite. Shy Sophie replied, “No, it will destroy my appetite” while Sincere Shamu commented, **“I think it would be interesting, but I’m not sure I would really want to know.** I would always be wondering what other people were tasting rather than enjoying my food with my own sense of taste.” Sincere Shamu’s tone seemed intrigued in knowing but not fully convinced.

Of all the participants, only Jovial James agreed that it would be interesting to know for “curiosity’s sake” but did express ambivalence by saying with a smile, “doesn’t matter either way.”

Insights

For the most part, the participants seemed very uninterested in this category and some even turned hostile (Genius George and Honest Hector) throughout the remainder of the interview. The hostility seems to be directed at content that doesn’t deal with mortality and preventative measures. Even Jovial James, would responded kindly, seemed disinterested in the remainder of the categories.

By this point in the interview, it seems as if many of the female participants, specifically Sincere Shamu and Shy Sofie, are interested in more natural lifestyles as both have expressed concern over unnecessary modifications outside of situations dealing with life and death.

Content for DNA Communities should focus primarily on situations dealing with significant health-related diseases that cannot be controlled but can be prevented or detected early.

Participant Interest in Personal Genetic Risks to Slow or Fast Caffeine Processor

Table 7: Participant’s Interest in Genetic Risks to Slow or Fast Caffeine Processor

Pseudonym	Slow or Fast Caffeine Processor	Comments
Genius George	No	“Seems a little obvious.”
Sincere Shamu	Yes	“During the interview I said no, but I didn’t hear the moderators say the part about that relating to my ability to get rid of other toxins. I think that is very interesting and I would definitely want to know.”
Shy Sophie	Yes	“I’d like to know. Sometimes my heart beats faster after I drink coffee.”
Jovial James	Yes	“I think you’d figure it out on your own anyways over time so it doesn’t matter, but yeah I’d probably say so.”
Honest Hector	No	“You’d know that after one cup.”
Confident Corey	NR	No response provided.
Exuberant Xena	No	“Would not matter I don’t drink caffeine.”

Overall

The participants expressed very little interest in this content with two of the participants acting particularly irritated and hostile. One female participant, Exuberant Xena, expressed her opinion that it didn't apply to her because she did not consume caffeine. Of the group, all three male participants suggested that the answer would be fairly obvious.

For the participants interested in learning more, only one female, Shy Sophie, expressed unwavering interest in this content. The other two, Jovial James and Sincere Shamu, were mixed. In particular, Sincere Shamu responded during the interview that she would not like to learn more but discovered through the online survey that there was more to the topic than originally discussed by the moderators. This new information caused her to change her opinion.

Details

At this point, two participants in particular, Genius George and Honest Hector, treated this topic rather hostilely responding with sarcastic comments that it "seems a little obvious" and "you'd know that after one cup" respectively. Both individuals seemed rather uninterested in discussing further.

Jovial James agreed with the other male participants (although with a kinder tone) that individuals could probably figure it out without the knowledge by saying, "I feel you'd figure it out on your own anyway over time so it doesn't matter."

Of the female participants, two out of three expressed interest in learning more about genetic disposition to slow or fast caffeine processors with the one participant in disagreement, Exuberant Xena, stating that she "doesn't drink caffeine." Shy Sophie stated that she would like to know because she finds that sometimes her "heart beats faster after drink[ing] coffee." Although Sincere Shamu originally stated that she wasn't interested in the content during the interview, she explained through the online survey, that "during the interview I said no, but I didn't hear the moderator say the part about that relating to my ability to get rid of other toxins. I think that is very interesting and I would definitely want to know."

Insights

Throughout this section of the interview, **all of the male participants seemed to think that genetic dispositions to slow and fast caffeine processors were obvious** with two of those participants, Genius George and Honest Hector, acting particularly hostile.

Other than Exuberant Xena, who did not consume caffeine, and Confident Corey, who did not respond, the other **females seemed rather receptive to learning more about caffeine processors citing that they would like to know more about how their body processes caffeine.**

From this section of the interview, it becomes obvious that **the male participants aren't very interested in genetic risks related to consumption but rather more interested in prevention. The female participants are more receptive to understanding healthy consumption in conjunction with prevention of disease.**

Recommendations for DNA Communities would include adding content that reflects more serious diseases and can provide necessary recommendations for education and prevention.

Participant Interest in Personal Genetic Relationship to Maternal and Paternal Ancestry (15000 Years Ago)

Table 8: Participant's Interest in Genetic Relationship to Maternal and Paternal Ancestry (15000 Years Ago)

Pseudonym	Maternal & Paternal Ancestry (15000 Years Ago)	Comments
Genius George	Yes	"I guess so, because it's a novelty."
Sincere Shamu	Yes	"We went to the houses they grew up in. It was just really interesting."
Shy Sophie	Yes	"I am interested."
Jovial James	Yes	"I'd probably say yes, I don't really care that much."
Honest Hector	Yes	"I think for me, being an African American, it would be significant."
Confident Corey	Yes	"I don't really care that much. What he said about slavery...I know enough to how they were..."
Exuberant Xena	Yes	"Yes, because sometimes I question my ethnicity."

Overall

There was unanimous interest by the participants that they would like to know more about their maternal and paternal ancestry from 15,000 years ago; however, the interest level varied.

Genius George, Jovial James, and Confident Corey all expressed interest but explained that they either didn't "really care that much" or that "it's a novelty." Based on the results, **the participants who were male Caucasians were the least interested in their ancestry while the three African-American participants were interested based on historical backgrounds** (although Confident Corey stated that she "don't really care that much").

Finally, **the four female participants were the most interested in learning about their ancestry** with Confident Corey serving as the least excited of that group.

Details

While everyone seemed engaged with the dialogue about ancestry, the amount of interest in learning more about their genetic history varied based on the participant.

The male Caucasian participants were least excited about discovering their ancestry. Genius George reluctantly replied, “I guess so, because it’s a novelty.” Jovial James followed this by stating, “I’d probably say yes, I don’t really care that much.”

Conversely, Honest Hector, who had previously been disengaged with the conversation, enthusiastically stated, **“I think for me, being an African American, it would be significant.”** Although Confident Corey seemed less excited as she “doesn’t really care that much”, she agreed with Honest Hector that this would be interesting to discover although she already knew “enough to how they were.” Similarly, Exuberant Xena expressed her interest because she “sometimes question[s] [her] ethnicity.”

Shy Sophie and Sincere Shamu were also very excited on the topic of ancestry. Sincere Shamu briefly described her experiences traveling to England and seeing some of her ancestry which was “just really interesting.”

Insights

For this part of the discussion, it became apparent that ethnicity was a factor in determining a participant’s interest in their ancestry. The male Caucasian participants, Jovial James and Genius George, expressed interest in learning more about their genetic ancestry but weren’t as enthused as the African-American participant, Honest Hector, who described it as **“significant.”**

Similarly, three female participants, Sincere Shamu, Shy Sofie, and Exuberant Xena, were very enthusiastic about their ancestry with Exuberant Xena revealing that “sometimes I question my ethnicity.” Confident Corey, while not as enthusiastic as the other female participants, agreed with Honest Hector on the importance of the historical nature of their ancestry but stated that “I don’t really care that much.”

For DNA Communities, it is suggested that this content remain included as it generated a lot of interest; however, careful understanding of target audience is imperative. This topic appealed more to females and minorities than it did to male Caucasians. Reasons this was appealing across the board, however, are **indicative of the personal relevance** it presents. Unlike some of the other areas, everyone has ancestry and this subject is a broad enough area to remain appealing for most demographics. **As content for DNA Communities is developed, it must be noted that more areas in genetics that impact everyone, such as ancestry, should be included.**

Participant Interest in Personal Genetic Risks to Breast or Prostrate Cancer

Table 9: Participant’s Interest in Genetic Risks of Breast or Prostate Cancer

Pseudonym	Risk of Breast or Prostrate Cancer	Comments
Genius George	Yes	“Yes, I would want to know so I could be more cognizant of signs and have myself checked more often.”
Sincere Shamu	Yes	“Yes, I would want to know, because you can easily check for that cancer and monitor your body. For other kinds of cancer, like pancreatic cancer which has no symptoms, I’m not sure I would want to know. I try to live healthy anyways, and if I knew I was at a high risk for a not easily detectible kind, I think it would ruin my quality of life.”
Shy Sophie	Yes	“Yes. Then I can go to hospital early.”
Jovial James	Yes	“So yeah, cuz there’s always prevention and stuff that you can do to lower the risk and stay head of it. You can change your lifestyle to significantly change risk.”
Honest Hector	Maybe	“I’m kind of torn...but if it’s going to get me anyway...if we’re talking quality of life it might be better just to live.”
Confident Corey	Yes	“I absolutely would.”
Exuberant Xena	Yes	“Yes, it’s just something that’s good to know.”

Overall

Of all the topics, **all the participants seemed to feel that this was the strongest category of interest.** All of the participants seemed to be **actively engaged** in the dialogue and **advocated for knowing about genetic risks in order to seek early prevention.** **Three out of the seven participants revealed that they had some family member who has lived with or died from prostate or breast cancer.**

Details

During this discussion, it seemed as if all the participant hostility had disappeared and everyone seemed somewhat somber. Three participants, Exuberant Xena, Jovial James, and Confident Corey described family members who have had breast and prostate cancer.

Many participants expressed a **concern over seeking early detection and prevention.** Jovial James noted that **“there’s always prevention and stuff that you can do to lower**

the risk and stay ahead of it” and that **“you can change your lifestyle to significantly change risk.”** Shy Sofie agreed and stated that early awareness would mean that she could **“go to hospital early.”** Similarly, Genius George expressed his concern by saying, **“I would want to know so I could be more cognizant of signs and have myself checked more often.”**

Despite agreeing with the desire to know about genetic risks related to breast or prostate cancer, Sincere Shamu and Honest Hector expressed concern over **ruining their quality of life.** Sincere Shamu said, **“I would want to know, because you can easily check for that cancer and monitor your body.** For other kinds of cancer, like pancreatic cancer which has **no symptoms, I’m not sure I would want to know.** I try to live healthy anyways, and **if I knew I was at a high risk for a not easily detectable kind, I think it would ruin my quality of life.”** Following this logic, Honest Hector stated, **“I’m kind of torn because my brother is a chemist and he always said if you live long enough you’ll die of cancer...but if it’s going to get me anyway...if we’re talking quality of life it might be better to just live.”**

Insights

The discussion in this section of the interview was very thoughtful and everyone seemed engaged. Three of the seven participants had loved ones afflicted with either breast or prostate cancer. This fact confirmed that the **participants are more engaged when the discussion is related to something personally meaningful.** With that said, it was also interesting to note that the **participants with afflicted loved ones did not bring this up during the online survey which is indicative that an online forum such as DNA Communities might not extract these types of personal stories.**

A central theme that emerged through this discussion was the idea of prevention of a fatal disease. While Genius George and Honest Hector had previously reacted hostile to topics without this theme, they were fully engaged in this conversation.

Another issue that emerged was the **concern over ruining quality of life** in order to obtain knowledge. Sincere Shamu, to this point in the interview, has mentioned this several times as have many others. Honest Hector was also concerned this time stating that **“if we’re talking quality of life it might be better just to live.”**

With these themes in mind, it becomes more obvious that the **participants do not want merely content that educates but rather helps them detect early and prevent potentially fatal diseases.** As exemplified by this conversation, **many participants have had first-hand, personally relevant experience** with this subject in genetics and were subsequently engaged. **Subject content should therefore reflect personally relevant subjects in genetics that focus on preventing serious or fatal diseases; simply providing the audience with an ominous forecast does nothing but ruin the quality of life and frustrate the user.**

Participant Interest in Personal Genetic Risks in Resistance to Malaria

Table 10: Participant’s Interest in Resistance to Malaria

Pseudonym	Resistance to Malaria	Comments
Genius George	No	-
Sincere Shamu	No	-
Shy Sophie	No	-
Jovial James	No	-
Honest Hector	Maybe	“Sure...”
Confident Corey	No	-
Exuberant Xena	No	-

Insights

Due to time constraints, this section was very limited. The only insights gained emerged during awkward laughter that expressed the participants’ collective opinion that Malaria was irrelevant to them. Only Honest Hector, with a somewhat sarcastic laugh, expressed slight interest. **Content should again reflect personally relevant diseases and conditions.**

III. Social Issues

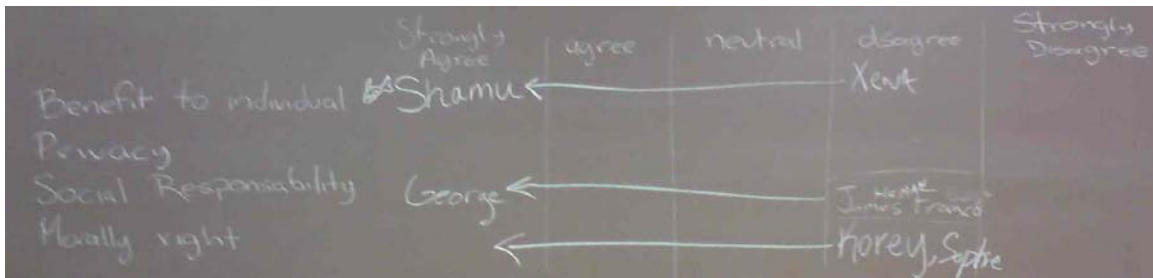
Participant Perspectives on Social Issues

Table 11: Summary of Participant Perspectives on Social Issues

Pseudonym	Should Genomes be Patented?	Should a Parent see their Child’s Genome?	Is it Ethical to Deny Access to Life-Extending Drugs Even if They Would Only Gain at Most 2 Weeks of Life?
Genius George	No	Maybe	No
Sincere Shamu	No	No	No
Shy Sophie	NR	No	NR
Jovial James	No	Maybe	No
Honest Hector	No	Yes	No
Confident Corey	No	Yes	No
Exuberant Xena	No	Yes	No

Summary

This section explores the participants' views on several issues including **patents on genomes, a child's right to genome privacy, and the ethics on denying access to life-extending drugs even if the extended time is short.** Participants feel **very strongly that most of the scenarios are unethical.** Only a few participants are supportive of parent's seeing a child's genome and that is purely for **early detection and prevention of diseases.** The participants were asked to write their names on a chalkboard. Due to time constraints this was only done once.



Many insights are revealed in the following graphs. The primary recommendation for this section is for the DNA Communities to **develop key positions on where the designers stand on certain issues.** With positions decided in these three areas, the DNA Communities project **can develop interactive stories or other forms of media that attempt to persuade the audience members to consider a different viewpoint and potentially accept a specified call to action.** If the intention is persuade the audience to accept patenting of genomes as ethical, a story-related content that reveals how a patented vaccine prevented a child's death can have a strong appeal as evidenced by Scenario 2.

Similarly, if the position is to persuade the audience to think that denying a life-saving drug to someone with only two weeks of life left as a maximum is the goal, then DNA Communities should pick interactive media that supports this.

The focus remains on determining a specific position in order to develop interactive content.

Participant Perspective on Patentable Genomes

Table 12: Participant’s Perspective on Patentable Genomes

Pseudonym	Should Genomes be Patented?	Comments
Genius George	No	“I don’t think the human genome should be patented.”
Sincere Shamu	No	“I don’t know, I guess I kind of feel both ways...someone did come up with that...but at the same time you can’t patent vaccines and other medical ideas so I guess no I disagree.”
Shy Sophie	NR	Response could not be heard.
Jovial James	No	“I disagree.”
Honest Hector	No	“I’m not sure that I want to give away my rights to my body to anyone else.”
Confident Corey	No	“Disagree.”
Exuberant Xena	No	“Disagree.”

Overall

Six out of seven participants were in agreement that **human genomes should not be patented**. It should be noted that this section of the interview was **susceptible to group think** as not many individual explanations were provided and many participants answered simultaneously. Of those six participants, only one participant, Sincere Shamu, offered mixed feelings as she “kind of feel both ways.”

Details

During the discussion the participants tended to provide very little feedback and seemed to participate with more group-think. Four out of seven participants, Jovial James, Confident Corey, Genius George, and Exuberant Xena, offered their position confidently and provided no further explanation.

Only one participant, Sincere Shamu, explained that she “kind of feel[s] both ways” as “someone did come up with [vaccines]” yet countered that she disagrees because “you can’t patent vaccines and other medical ideas.”

Honest Hector expressed concern that he did not “want to give away my rights to my body to anyone else.”

Insights

Most of the participants maintained a solid viewpoint that **genomes should not be patented**. Only one participant, Sincere Shamu, suggested that she can “kind of feel both ways” but even then countered herself by saying “I guess no I disagree.”

If the participants are meant to represent the general public, it becomes evident that there is minimal support for patenting human genomes even at the expense of limiting advances in biotechnology. Because not much feedback was provided, it is hard to recommend content for the DNA Communities project; however, the data that was collected suggests that the audience is opposed to patents. **DNA Communities must decide whether it wants to provide a call to action for these individuals in trying to appeal to government agencies to make patented genomes illegal or rather change the opinion of these individuals to agreeing that it is acceptable to patent genomes.** Providing interactive content in each of these directions can influence the users.

Participant Perspective on a Child’s Right to Genome Privacy

Table 13: Participant’s Perspective on a Child’s Right to Genome Privacy

Pseudonym	Should a Parent See Their Child’s Genome?	Comments
Genius George	Maybe	“I would turn into “an agree” if there were more that could be done...I agree if you find out your kid won’t end up past the age of 13...I disagree until the point that you can actually do something with the results besides wait.”
Sincere Shamu	No	“I also disagree...even if the mom knew it was the child that had the heart defect...it kind of limits people’s potential.”
Shy Sophie	No	“I disagree, I don’t think I have the right.”
Jovial James	Maybe	“You could be a better parent.”
Honest Hector	Yes	“I also strongly agree. I think, having a baby, if you find out your child is predisposed to something...I think I would definitely want to know...I don’t have to tell anyone, but I would definitely want to know.”
Confident Corey	Yes	“I strongly agree too...you don’t have any privacy when you’re 10. After you’re 18, if you wanna know, I’ll tell you.”
Exuberant Xena	Yes	“I agree that parents should because I wanna know if I’m going to have to pay hospital bills now or later...if they have some type of disease I would like to know if I could prevent it.”

Overall

Five out of seven participants agree in some form that **knowing a child’s genome is helpful**. Of those five participants, **all three males agree in some form**.

All three African-American participants, two female and one male, agreed that a parent should see their child's genome.

The two Caucasian male participants half-heartedly agreed. Jovial James believes knowing could make you a "better parent" while Genius George believes it is only **acceptable if "you can actually do something with the results besides wait."**

The two dissenting female participants, Sincere Shamu and Shy Sophie, do not believe a parent has the right to know their child's genome.

Details

The three African-American participants emphatically expressed their desire to know their child's genome. Honest Hector explained that it is important to "find out [if] your child is predisposed to something." Similarly, Exuberant Xena explained that she would want to know "if they have some type of disease" that could be prevented and if she is "going to have to pay hospital bills now or later." While Confident Corey didn't elaborate her explanation, she justified her right by suggesting that a child doesn't "have any privacy" early on in life.

The two Caucasian male participants seemed somewhat mixed on whether a parent should have the right to know. Jovial James thought it could improve parenting skills while Genius George offered a mixed view. Genius George commented that he would "agree if there was more that could be done" such as if "you find out your kid won't end up past the age of 13." He elaborates further that he disagrees "until the point that you can actually do something with the results besides wait."

The two female participants in disagreement, Shy Sofie and Sincere Shamu, believe that a parent doesn't have the right to discover a child's genome. While Shy Sofie doesn't offer more insight than "I don't think I have the right," Sincere Shamu thinks knowing "kind of limits people's potential."

Insights

A majority of the participants agree that knowing a child's genome can help with parenting skills and in taking preventative measures. One participant, Exuberant Xena, also justified knowing a child's genome in order to prepare for **"pay[ing] hospital bills now or later."**

All three African-American participants advocated very strongly for knowledge of a child's genome and the two male Caucasians both half-heartedly suggested that it could help only under certain conditions.

Of those that disagreed, both were female participants and similarly justified their reasoning for not wanting to know because it could be destructive for the development of their child.

With these insights, the recommendation for the DNA Communities project would be to **consider the ethnicities and gender of the target audience**. All three African American participants strongly agreed while two female participants disagreed. **Including content such as testimonials of children that were saved because parents knew their child’s genome should generate a lot of support and potentially persuade the two male Caucasian participants to commit to supporting this viewpoint.**

Participant Perspective on Denying Access to Life-Extending Drugs

Table 14: Participant’s Perspective on Denying Access to Life-Extending Drugs

Pseudonym	Is it Ethical to Deny Access to Life-Extending Drugs Even if They Would Only Gain at Most 2 Weeks of Life?	Comments
Genius George	No	“I would say it was unethical, even to the people.”
Sincere Shamu	No	“I disagree with that ‘cause...the reason they are denying people is because it only extends two weeks. First of all, that isn’t finite. That’s just what they think. It’s just not morally right.”
Shy Sophie	NR	Response not clear.
Jovial James	No	“I guess I would disagree because of the morally right thing, it’s their choice.”
Honest Hector	No	“Ditto.”
Confident Corey	No	“Same thing.”
Exuberant Xena	No	“OK I disagree because it’s morally right.”

Overall

Except Shy Sophie, who wasn’t audible, there was **unanimous consent that it is unethical to deny access to life-extending drugs even if individuals would only gain at most two weeks of life**. Very little discussion took place outside of several participants reinforcing the point that it is important for an individual to have a choice.

Details

Not many individuals expressed much interest in the conversation or really justified their reasoning. When given the scenario, Sincere Shamu exclaimed, “first of all, that isn’t finite, that’s just what they think.” Jovial James, Genius George, and Exuberant Xena also used the phrase “morally right.”

Insights

All of the participants seemed to agree that it was unethical to deny access to life-extending drugs even if an individual would only gain at most two weeks of life.

Given the mutual consensus that it was unethical to deny life-extending drugs, DNA Communities could use this **discussion topic as a means of reforming health care policies**. By serving as a collective hub, DNA Communities can **add interactive content that features a sad story of someone getting denied health care in order to evoke a call to action for users**.

IV. Deliberation in Community

Participant Preferences for DNA Communities Deliberation

Table 15: Participant’s Preferences for DNA Communities Deliberation

Pseudonym	Interested in Voting?	Choose to see how others vote?	Do you care who votes?
Genius George	No	No	Mixed
Sincere Shamu	Yes	Yes	Yes
Shy Sophie	Yes	Yes	Yes
Jovial James	Yes	Yes	No
Honest Hector	Yes	Yes	Yes
Confident Corey	NR	Yes	Yes
Exuberant Xena	Yes	No	No

Overall

Of the seven participants, five were interested in voting on the DNA Communities project with Confident Corey not responding and Genius George hostilely responding, “Not interested in voting at all. I’m not certain that this would really have any impact on policy.” The other participants seemed interested in the site.

Five participants expressed interest in seeing what other people voted with a hostile Genius George and Exuberant Xena dissenting.

Three participants, two female and one male, expressed their concern over who votes. Several participants expressed interest in seeing a **“more diverse sample”** that use **“reasoning”** to justify their votes.

Details

Besides Genius George, who hostilely expressed that he was “not interested in voting at all” because he didn’t think it would really “have any impact on policy,” most of the members seemed interested in voting. Sincere Shamu, Exuberant Xena, and Shy Sofie all described their interest in the site. Jovial James expressed interest because he liked “that it’s **non-partisan and seems like an informative site where you can see different people’s opinions.**” Honest Hector believes the site is “**important to be aware of the implications**” and to be “**a part of the decision process**” in which “**policy makers would have [his] input.**”

Five out of seven participants expressed interest in seeing how others voted. Sincere Shamu commented that she would only be interested in seeing how voted if they were “**of some use or interest**” to her. She also noted that it is important to see “**what qualifies them to come to such conclusions and influence others**” and that she is only “**interested in why people’s opinions are what they are if they provide some research or interesting findings to support their opinions.**” Similarly, Jovial James explained, that “**people’s reasonings behind why could teach you more about the issues addressed and shape your own opinion.**” Along those lines, Honest Hector commented that he would like to “**see where [his] answers fit along the continuum.**” Expressing hostility, Genius George smugly replied, “I am not really interested in what the rest of the community voted for – or their opinions really.”

Of the participants, four members, Sincere Shamu, Shy Sophie, Honest Hector, and Confident Corey, expressed definitive interest in knowing who voted in the community. Sincere Shamu explains, “**I think who participates would definitely make the information more interesting to me**” because “**I would much rather read or listen to why a DNA researcher or some other party closely involved forms the opinions that they do, rather than some guy off the street.**” Shy Sophie expanded this by stating, “**A person that has professional knowledge will give more meaningful advice.**” Honest Hector moved in a slightly different direction by stating that “**policies could affect us all in different ways, I would prefer to see a more diverse sample.**” In even a different direction, Confident Corey stated, that she would want “**to know the financial situation of the people.**” Exuberant Xena seemed least interested in learning stating that “a person’s opinion is their opinion for a reason.” In contrast, Jovial James justified that “it’s nice to have...but reasonings seem more important.” Genius George was somewhat mixed. During the interview, he defiantly exclaimed, “just my opinion matters;” however, through the online survey, he stated “yes it would” make a difference because he **wouldn’t “want all the focus to be on one particular set of genetic issues (by race, etc.)”**

Insights

Other than Genius George, who was already disengaged, the participants seemed excited about participating in a voting site that could impact policy. One consideration that was brought forth by Jovial James was the concept of “**non-partisan**” and **informative.**

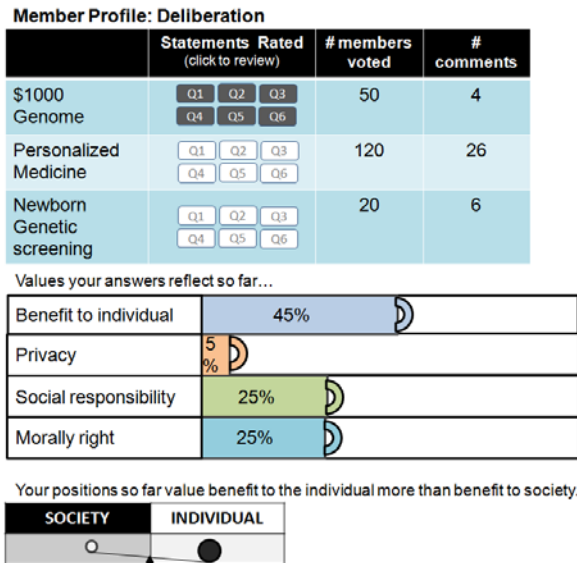
Daniel DeMaiolo
TC841 Design Research
Focus Group Analysis
2/20/2011

Previous recommendations suggested pursuing persuasive interactive content but this clearly would be unappealing to an individual like Jovial James. Although a direction is already explained by the moderator, the dilemma that faces DNA Communities is to **either confirm this purpose or change it**. While individuals like Jovial James describe their **interest** in a **non-partisan informative site**, others such as Honest Hector, believe that this project **can impact the “decision process” of policy makers**. As debates and opinions unfold, **will DNA Communities continue to stay objective and unbiased?** Or will the designers change the direction by **harnessing the power of voters’ opinions and use this to help change policy?**

Of the participants who expressed interest in seeing how others vote, Sincere Shamu, Honest Hector, and Jovial James expressed most interest in **“what qualifies them to come to such conclusions and influence others.”** Honest Hector explained that he would like to see where his **“answers fit along the continuum”** and Jovial James said that opportunities like this **“could teach you more about the issues addressed and shape your own opinion.”** These perspectives reveal that many participants **like** the idea of being able to see **how other people voted provided they have some strong reasoning and/or qualifications**. **While DNA Communities could and should include many opinions from random individuals, the project must also include credible sources as well.**

Four participants indicated they were interested in seeing who was apart of each community with two males, Genius George and Honest Hector, expressing concern over having a **diverse pool of participants**. Sincere Shamu also indicated her preference to **“read or listen to why a DNA researcher...forms the opinions that they do, rather than some guy off the street.”** The revelations in this section once again confirm that **diversity and credibility are important factors in designing an effective forum where users can share their opinions.**

V. Member Profile Draft



http://msuTelecasters.dnaroulette.org

21st Century DNA

About Games Deliberation Ask Science My Profile

Welcome back, *Genie*.

•Your most recent DNA roulette game was **SICKLE CELL ANEMIA**.
 •Your most recent deliberation was **PERSONALIZED MEDICINE Q4**.

Ask a *Geneticist* question of the week: Will two redheads produce only redhead children?

Leader Board
 (recent top scores)
 alphawolf eye color 300
 xyzxyz type 2 diabetes 240
 gamegrrl height 240

Want to play against others?
 Click to join a multiplayer game to play with other members now.
[Join multiplayer game](#)

NEW Deliberation Averages
 (some questions you already answered have new community averages – click to view)

\$1,000 Genome
 Q1 Q2 Q3

Overall

During the conclusion of the interview, participants were shown two graphics for the DNA Communities project. It was difficult to hear many of the responses as both pages were passed around with participants commenting at random. Many of the participants were **confused and frustrated** and a few asked specific questions related to the comments section. Some suggested **color coding** and clarifying design elements as well as **making the game more clear**.

Details

Related to the graphic to the left, Confident Corey stated that if the users couldn't see the comments, she doesn't "understand why its there" and **"if we can't see the comments, no need for it to be there."** Genius George expressed apathy at the graphic and Honest Hector, in a frustrated tone, exclaimed, "I'm not getting very much from this!" and **"it seems complicated."** Confident Corey **liked the chart with percentages best** and Honest Hector did concede that **"aesthetically, [it's] easy to understand."** Sincere Shamu also agreed that **"it would be most helpful if we could read the comments."** In terms of design, Honest Hector suggested "maybe **color coding things**, because it makes it **stand out more.**" One participant even exclaimed, **"this is sort of a game that I haven't really gotten the idea of."**

Related to the graphic on the right, participants expressed **more confusion**. Honest Hector exclaimed, "just looking at it, I'm not sure what's going on." Confident Corey reinforced the group confusion by trying to explain each part of the diagram until eventually saying, "I don't know. It's very confusing...**very vague.**" Sincere Shamu

offered advice by suggesting that “it would **help to know which of these tabs we’re on so you know where you are on the site**” and Confident Corey also offered, “it **should be fun, but not too much...otherwise it takes away from the information.**” Genius George criticized the graphic by saying, “**I don’t see an inherent call of action on the website of any sort.**” Honest Hector emphasized not making it animated as “**simple is always better.**”

Insights

Unfortunately there wasn’t ample time to really dissect what was wrong with each graphic as time was running out and participants were shouting answers. One thing is clear – not many participants understood the navigation let alone the game. Almost all of the participants **were ambivalent or frustrated.**

Recommendations for design considerations in DNA Communities include: **use of color coding, simplifying number of options, making tabs distinctive, and emphasizing a call to action.**

Recommendations

Expressing his disinterest, Genius George replied, “I’m not sure if it matters...it’s pretty insignificant.” This statement describes just one participant’s reaction to one of many potential subjects for the DNA Communities project to include; however, it reveals something very important about selection of content – it must be personally relevant, meaningful, and have a significant impact on the user’s life in which the user can adjust their lifestyle or seek early detection and prevention.

The findings reveal participant reactions to different pieces of content, their perspectives on social issues, their preferences for voting inside the DNA Communities, and their reactions to initial designs for the project. Careful choice of these elements will determine the success of DNA Communities and inevitably decide “it if matters” or if “it’s pretty insignificant.”

Recommendations include:

1. Genetics content should be personally relevant, meaningful, and have a significant impact on the user’s life. This means that obtaining this knowledge will allow the user to adjust their lifestyle and/or seek early detection and prevention.
2. Avoid raising awareness about diseases or conditions that have no form of intervention as it will cause users to only ruin their quality of life.
3. Clearly identify a more specific target audience.
4. Commit to a persuasive or informative stance. With many participants expecting a call to action, DNA Communities has the potential to harness many different viewpoints to advocate for policy changes.

5. Develop interactive content which provides either an objective perspective or reinforces a message depending on if DNA Communities decides to stay informative or become persuasive respectively. For example, if DNA Communities wanted to illustrate the benefits of patenting genomes, the designers could create a game or other form of media which highlights how patented genomes result in advances in medicine. If DNA Communities remains informative, it can provide a media product which objectively highlights both perspectives.
6. In the DNA Communities forum, make sure to include opinions from a variety of diverse individuals on a variety of genetics issues. Also, it is important to include opinions that are well reasoned and sometimes come from professionals/experts.
7. Simplify the navigation and use color coding. The tabs should also be distinguished.
8. Provide clear goals and objectives for the game.
9. Emphasize a call to action or purpose.