Use this form to provide your answers, leaving the questions in bold, and your answers in normal font or clear handwriting. Pls do not add or remove lines, if you need extra space, use the back of the page.

Watch the video Cracking your genetic code from NOVA, available at: https://www.youtube.com/watch?v=d_zBGB2r8Wc **and write a paragraph (10 to 15 lines) to convince me that you saw the whole video and that you understood it.**

I was fascinated by the video Cracking your genetic code from NOVA. This video helped me understand the scope of Genome Sequencing and what can be achieved by this. At the same time it also presented views that this is relatively a new field and we have not progressed much to understand the real utilization of Genome Sequencing. The possibility of doubt was also shown. Multiple cases were discussed where this technology has helped save life for example - Nick, where there was a single letter change in his Genome and understanding this helped him over come his illness. Miracle drug for CF patient. The case of Noah and Alexis who suffered from Cerebral Palsy and how they were completely cured from this condition also bring to light what Genome sequencing can achieve.

The case of Steve who was fighting Melanoma is a best example for our lack of knowledge in this field. Steve was able to fight Melanoma using this new technology, but the cancer cells are returning and becoming more resistant to treatment.

The technical difficulty associated with decoding the Genome was also discussed. It explained about the computational difficulty and how an error can occur in this computation. It also explains that Genome Science is not an absolute science as there is a huge scope of error while Genome Sequencing is done. New Companies working based on Genome Sequencing also showed the Monetary scope of this field.

One striking insight was the example of Katie Moser who is a volunteer at Huntington's disease Society & Megan Sullivan. This brings me to the question whether we are capable of digesting the information / knowledge that Genome Sequencing can provide. What if we know that in the later stage of life we are prone to diseases to which we have no cure. This would lead to a less pleasant life. The example of Catherine Elton also reinforce this idea. She has precise stated this as "The Burden of Knowing".

1. **Choose a 30 to 60 seconds segment that made the most impression to you.**
   a) **Specify at what place this segment is (i.e. 5 min 23 sec)**
      41 mins 00 sec
   b) **Write a paragraph (5 to 10 lines) describing why this segment impressed you**

   The case of Noah and Alexis who suffered from Cerebral Palsy has a great impression on me. The video explains how they were completely cured from this condition by Genome sequencing. This was a promise that the cure for some of the disease for which we have least knowledge can be found by Genome Sequencing. It also explained about how a condition can be treated by understanding the mutation in our body, and administering medication accordingly to these conditions. It was great to see people who were is a very crippled state of life returning to a normal healthy life.

c) Write a paragraph (10 to 15 lines) where you explain whether you would like to have your genome sequenced and why (assuming it won't cost you any $). Be prepared with a number of strong, convincing arguments to defend at class, both for being in favor or against of being tested.

In Favour:
I would strongly agree to the idea to have my genome sequenced. Some of the reason are - Firstly the analysis of Genome Sequencing is able to provide a quantitative probability of the disease or health condition that can happen to me. This would help me to be better prepared to face the future. I can take medication, plan a new routine/ lifestyle in such a way that the probability of me getting sick can be brought down. Even if I eventually get some of these diseases I can be in a better prepared condition then, when I am not prepared at all. Secondly, It helps me plan for my future generation. For example if I have a condition that I am not aware of and there is a possibility of passing this to the future generation, then I can make a decision which can prevent this. Lastly out of curiosity. Only a handful of people have there genome sequenced.

Against:
This is a new field of science, there are no strong evidence that this can be perfect. The possibility of error in Sequencing outweighs the accuracy. Most of the company are profit motivated, sequencing are done only on part of your gene hence sequencing does not give a complete picture. If we know that we eventually in life would get some incurable diseases then, its better not to know. The knowledge can be a burden many times. After all, these are just probability, these are not absolute science.

d) What do you think is the relationship between Computer Science and these genomic issues, and how is this relevant for computational scientists, and to this seminar in particular (5 to 10 lines)?

One of the major concerns about Genome Sequencing is Genome "sequencing" itself. A single person's genome consist of thousands of literals and our systems are not proficient enough to decode and illustrate all of them. It is a very time consuming process with a wide probability of error. This is the relation between Computer Science and genomic issues. As a computer graduate I feel that we need to develop systems that are efficient to do the computations involving the genome with minimal error. I feel like the seminar should be focused on these topics. The computational difficulty in Genome sequencing is an open ended question that need answers. The databases and high processing powers are needed for genome sequencing. Hence In short in my opinion the seminar should be focused on unlocking efficient methodology to decode genome in a cost efficient manner so that the normal people can be able to get the benefits of this service.

2. **Surf the web to learn about 23andme beyond the little information that appeared in the video and beyond the paragraph you wrote for the assignment described in class, especially to learn about the recent developments that have been widely covered in numerous sites.**

   a) **Make a list of at least 7 sites which were the most informative and for each site write 2-3 lines describing what they are about. Specify the site name and title, not only illegible urls, and state briefly what you learned in each of them.**

      1. Wikipedia ["23andMe"] - A good summary of the products of 23andme was explained in Wikipedia. The clashes between FDA and the company was also explained with timeline. The current happening - administrative and scientific - was also discussed here.
      [https://en.wikipedia.org/wiki/23andMe]

      2. 23andme [https://www.23andme.com/] - The official site is attractive which aims at the user experience. The website is interactive and easy to navigate which shows the marketing side of 23andme. The price listing was also attractive. Site contain a basic outline of their techniques. The ancestry service focus the more casual customer.

      3. Scientific American ["23andme is terrifying but not for the reasons the fad thinks"] - An illustrative article is presented about the conflicts between 23andme and FDA. Subjects about implicit and explicit customer right in Personal Genome Service was discussed. A comparison on how Google break such promises for monetary benefits is discussed.
      [https://www.scientificamerican.com/article/23andme-is-terrifying-but-not-for-the-reasons-the-fda-thinks/]

      4. Fast Company ["Inside 23andme founder Anne Wojcicki's $99 DNA revolution"] - A descriptive article on 23andme was presented. It explained how Anne Wojcicki's (CEO of 23andme) was able to bring up such radical idea and her motivation for this business. Multiple examples on Personal Genome Services was explained
      [https://www.fastcompany.com/3018598/for-99-this-ceo-can-tell-you-what-might-kill-you-inside-23andme-founder-anne-wojcickis-dna-r]

      5. Forbes ["23andStupid: Is 23andMe Self-Destructing?"] - An insightful article on the benefits of 23andme on science community. This article was more in favor of 23andme and how FDA should accept such a company to operate.
      [http://www.forbes.com/sites/matthewherper/2013/11/25/23andstupid-is-23andme-self-destructing/#70d677c63aa0]

      6. The New Yorker ["The F.D.A. vs. Personal Genetic Testing"] - The article is about the conflicts between FDA and 23andme. It explains how FDA has objected the personal genetic testing that is offered by 23andme.

      http://www.newyorker.com/tech/elements/the-f-d-a-vs-personal-genetic-testing

      7. Business Insider ["I tried 23andMe's new genetics test — and now I know why the company caused such a stir"] - This article reinforce the idea that 23andme is based on probability test and many times these can be false. This article explains the step by step process in which the author has done the test. The result interpretation was also explained.

      http://www.businessinsider.com/i-tried-the-new-23andme-genetic-test-2015-12/#a-few-days-after-ordering-my-box-arrived-it-was-colorful-and-so-inviting-that-i-couldnt-wait-to-open-it-up-1

   b) **Write a paragraph (10 to15 lines) summarizing what you have learned about 23andme (what is the current controversy, what are the latest news, and what you think about it, etc)**

      The above article helped me understand the controversy associated with 23andme and how this test works. One understanding was the real cause of conflict between 23andme and FDA, the issue was in which 23andme predicts the medical conditions. According to FDA a medical advice can only be given by a qualified source and 23andme cannot be qualified which was the real cause of concern as it lacks legally required regulatory approvals. 23andme website illustrates numerous examples about people getting recognized with health conditions, these are considered as medical advice by FDA. Numerous conversation were done between the 2 parties and things were not so good between both. The personal genome testing and ancestry testing was illustrated in the company website. Many of the experiences by people are that these are no an absolute result but things that are based more on probability. There are a high chances that these can be wrong as well.

One of the concern stated was the insecurity of these personal data. These data in wrong hand can cause issues. Like if the insurance company is able to get these details then things can be different. These are sensitive information and should be protected. Hence we need regulations for these company. These question emphases the monetary motives of this company. If they are providing these test at a minimal cost how do they earn profits. The example of Google is an eye opener. The company had one of the best policy of customer rights regarding safe guarding of customer information. But today Google make millions of dollars in revenue by selling the same old customer information/data that once was once very crucial part of the company.

c) In your opinion, what are the 3 main arguments to support FDA's decision?

1) The company need to be regulated as the test results can be misleading to people. The equipment, methodology used for the test needs to be standardized. The results are not accurate enough.
2) The security of the customer sensitive data is of concern. There should be very strict rules regarding how these data are to be shared with a 3rd party entity. Hence FDA can play a crucial role in regulating these company.
3) Regulatory board should have control on these company as there can be situation where the economy driven by profit can create an environment where the people are cheated. For example the test results by 23andme can present a certain disease and there can be collaborations between medical companies, hospital such that the treatment should be taken from a certain institute or company medicine. This can lead to a society that makes people believe that they are sick and should be on medication at all times.

e) What are the 3 main arguments to support 23andme?

1) Its better to know the risk factor in our life so that we can led a more regulated life style. Once we have a probability of the risk factors in our life we can better prepare for future.
2) Companies like these can be helpful in identifying cure for incurable diseases. The data collected from the numerous test participants can be analyzed to bring about traits. These can be studied to understand the real causes of the disease. Understand the risk groups and generalizations can be made.
3) Genome sequencing is a new field, and there are much to be learnt. Companies like this can help people understand more about these field and its scope. Companies like these can conduct studies and create new methodologies.

f) Write a paragraph (10 to 15 lines) describing what is your opinion about what the FDA should do and what 23andme's future should be

I think that FDA is correct in its decision. The service offered by 23andme are not absolute and there is a huge probability of error which can be misleading to people. The main issues are when people takes the results by 23andme as medical advices. I strongly believe that companies like these needs to be strictly regulated as the data that they gain from each customer are of very sensitive nature. These data if not regulated can fall into wrong hand and can be used for monetary benefits. For example if insurance, rental, hospital etc. can get these data then things would be bad. The whole economy would be driven by these data. The insurance rate of a person with a high risk can go high incredibly. These can cause economic stability. For example, how Google uses our data is of concern. The data can be sold for a huge sum.

The nominal rates of the test offered by 23andme creates doubt in me. If they offer such a low cost test the authenticity of the results has to be doubted. How do these company earn profit? In my opinion they would by selling the sensitive information to third party entities. Once they have a good number of data, then these data can help identify the risk groups in a society. Hence to conclude FDA should also consider the security of these sensitive data as well and regulate the company so that these data are not used for sole monetary benefits by other companies.

3. **If you were offered the services of genepeeks, the perfect 46, yad yeshurim or 23andme for free would you like to be tested? In which situations? Why or why not? Notice this is a different question than 1c above. There you are asked about sequencing your whole genome. Here you are asked to get the info from these companies, which is not the same as the whole genome sequencing. Make sure you understand the difference. State in your answer how the info you get is different from your whole genome, and explain how (and if) your answer to 1c is different.**

I might give a try, but would not take them for granted or seriously. I have a feeling that these companies are profit motivated. The whole concept that these company works on is different from the whole Genome Sequencing. In the later we get a complete image of our genome, but these company just work on a part of our genome and provide a report with the probability of heath conditions that may occur in future. They work by targeted Genome sequencing, where the focus would be on a part of the Genome rather then the whole Genome.
So Firstly these assumptions are based on an incomplete picture and these result are just probabilities. So the info that I get from them tends to be more false them being true. I would use them as a general guide line and bring in a minimal amount of change in my life to accommodate these advices.

4. **If you were looking for a job, and a company of the ones above would have offerings, would you like to work for them? If there was a new startup for a company like the ones above looking for CS people like you, would you be interested? If you remain in academia, would you be interested to belong to their board of advisors? Explain your answers (not just a Yes or No).**

Even though these company provide a rich experience in this field I personally would hesitate to join them. I believe that this is a current field and the knowledge that we have in this field is limited. And companies like these are driven by profit. So this is a dangerous mix, profit-making on limited knowledge. This is a field that has to be studied in depth in academia, and not something that has to be sold for monetary benefits.
It would be of least interest to me to join a startup company in this field. The above resons holds for this question as well.
I would be interested to be an advisor in the board, as I can advice changes. I can try my best to help bring awareness to the wide possibilities of this field.

5. **Optional: watch the Gattaca movie, if you still haven't done so. STRONGLY ENCOURAGED. If you write a nice summary of the movie it may grant you some bonus too.**