

Lab 1: Ethical Software Engineering

LAB PLAN

Before we started the exercise, we decided first which case we want to discuss. We ended up with case 4. Then we read the case individually. After that, we discussed the questions and found ideal (in our opinion) answers for every question. At the end, we also created a poster to describe our case.

Case 4: Genetic Data

A company was started in Iceland in 1996 and was working on determining genetic markers for specific diseases. When the human genome was sequenced in 2003 the company began storing the data for all of the inhabitants of Iceland.

There are only 300.000 inhabitants and they are quite strongly interrelated. In addition, the government has a lot of publically obtainable information about the inhabitants, that can easily be linked to other data using the tax number that every citizen is given. The Icelandic government also gave the company access to all health records in the country.

Icelanders are very enthusiastic about science and modern technology, and they willingly lined up to donate their data and DNA.

The company managed to set up a complete database, and was finding many interesting markers for certain kinds of diseases, and were successful in finding many markers for diabetes and some forms of cancer. But the Icelandic economy took a nosedive in 2008, and before long there was no money to continue the operation. The company filed for bankruptcy and began selling off assets to cover their debt.

The company was discovered to be in litigation against five former researchers, who left the company and moved to the United States, taking copies of the data with them. The researchers had been working on some long-year projects on determining predisposition to certain forms of cancer and were worried that the data might disappear if the company went broke.

An Icelandic woman had also sued the company to keep them from disclosing information about her and her now deceased father. Since she shares half of his genetic markers, releasing his health records would make information about her available. She won her case before the Icelandic Supreme Court, who determined that the company had not properly observed Icelandic privacy laws.

LAB PROTOCOL

Who are the actors in this scenario? There may be unnamed actors, and not all named actors are truly involved in the case.

Active actors	Passive actors
The Company	The Icelandic Supreme Court
Five former researchers	The next generations (of the inhabitants)
an Icelandic woman	Buyers of the assets
300 000 inhabitants	The deceased father of the woman
The Icelandic Government	-

So, we had some actors based on the scenario. We classified into two different groups. The groups are active and passive actors. Active actors are people who directly involved in the case, while passive actors are not involved in the case. One of the actors is **The Icelandic government** who has many information about the citizens in the country and they gave also an access health records to the companies in Iceland. Another actor is **the citizens of Iceland** themselves, who gave their data and DNA to the government for use as technological interest. The third actor is the group of **five former researchers**, who left and moved to the United States with taking copies of data. The other actor is **an Icelandic woman**, who won the case because she Icelandic Supreme Court adjudicated that the company did not keep the privacy laws.

We also found some actors who are not truly involved in this case. For instance, the **Icelandic Supreme Court** is not directly involved in the case, because their responsibility is to prosecute legal issues, not to keep the data privacy from citizens.

What are the ethical problems (not the legal problems) involved in this scenario?

The initial ethical problem is that the Icelandic government gave a private company access to all health records in the country and that there is already a lot of publically obtainable data about the population. The population was then obviously not “forced” to donate their data and DNA to the company and research in general, but apparently the government did not put any kind of regulation in place that would have ensured the data is kept safe in the future and is not transferred to third parties – neither by individual researchers taking copies of the database with them nor by the company “officially” selling off assets to cover their debt.

- Using private data without any permission → privacy conflict
- Citizens were unconscious → the data has been used in another way, that was established
- Connection between medical data and tax number → they should be separate, not everyone wish to publish their private health report
- The researchers took all the data to another country. It could impact on relations between two countries.

We discussed it in light of general ethical guidelines, for example the ACM (even though it's about computing professionalism, there are general principles) and found out that a plenty of general principles was contravened, such as **1.2 Avoid harm** (ACM Code of Ethics and Professional Conduct); **1.3 Be honest and trustworthy** (ACM); **1.4 Be fair and take action not to discriminate** (ACM) - speaking about the next generations and possible influence of the family history; **1.6 Respect privacy** (ACM).

What will happen if another company purchases the database from this company?

What are the ethical aspects of economic problems? Should the database be destroyed? What should happen in a case like this?

If another company purchases the database they will consider themselves the legal owners of the data and the affected individuals – possibly not even knowing who bought the database – would have even less control about what happens with their sensitive health data. There would also be no guarantee that any private company actually intends to use the data purely for medical research that would benefit the general public but could as well resell the data and use it for any kind of service that

would rate people based on their health – whether for job applications, insurance payments or potentially even more ethically troubling ideas of rating human life based on genetic factors.

Unfortunately most people without a strong value system tend to make more or less ethically critical decisions when they find themselves in economic problems – starting with using public transport without paying for a ticket to save money, all the way to companies and politicians collaborating with or supporting dictators, inhumane governments and unjustifiable wars in order to gain financial support or profit in return.

As regrettable as the loss of the data would be considering its potential benefit for medical research, it would be best to destroy it if the company or the government cannot guarantee that it will never be used for anything else than medical research. As long as the data is anonymized and in connection with the small size of the Icelandic population it is even more important to consider the potential long-term effects of the data ending up in the hands of anybody who might be able to identify an individual with full knowledge of their health status and genetic dispositions.

What could happen:

- Threats to national security. We cannot be 100% sure about tomorrow - especially when we speak about the politics. If the relationship between some countries is destroyed, the access to people private data could become one of the military advantages or something similar.
- Price manipulation in a medical market → possible consequence: economical crisis, weakness in medical market, deaths of people
- Ethical aspect: negative impact on younger generation - the next generation doesn't sign anything, but the researchers are still using their genome
- Someone could use the access to private data and sale it e.g. it could be use for drug selling, order illegal stuff with fake personal data, etc.

Speaking about the ways of solving the problem, it could be creation of some business/marketing which deals with the medical corruption, misuse and manipulation of the data.

We do not think that the base should be destroyed/not destroyed at all. In our opinion, all the people who share their data, must be asked about the future of the data, so we prefer to provide them an opportunity to vote, If someone wants their data to be kept - the concrete data must be deleted, but the data of the others is still in the base.

What should the researchers have done, when they saw their company in danger of going broke and their research threatened?

The researchers should have found a legal and ethical solution within Iceland first – maybe involving the Icelandic government or even the general public – to ensure all privacy laws are observed and sensitive data of basically the complete population is not transferred to another country.

We think that the researchers should inform and ask the government and people, whose data is actually used. Also it's necessary to ask the company - in order to keep the data safe. It should be discussed at the beginning of establishment, what should be done if the company went bankrupt.

What if companies could request that prospective employees submit a genetic record, similar to a credit record, showing them to be free of predisposition to certain diseases? What are the implications of this?

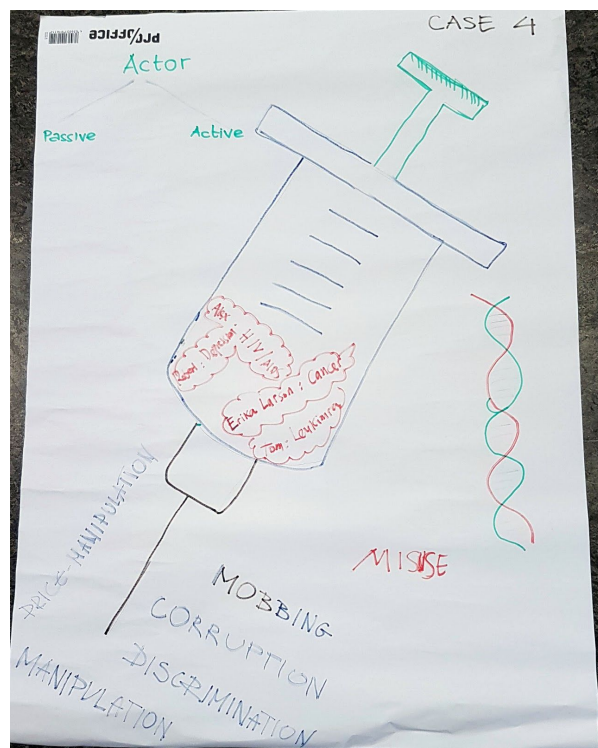
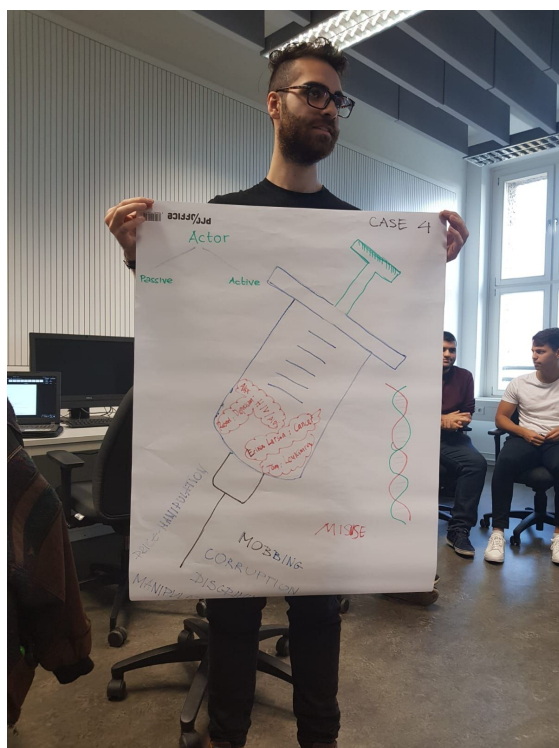
This would affect basic human rights and base the value of people and human life on their health status (or even just their potential health in the future). It would allow employers to only hire perfectly healthy people (because they have the lowest risk of sick days and further problems affecting the company's productivity), contrary to all anti-discrimination laws and basic ethical principles, putting human beings on the same level as machines like robots which are only valuable as long as they function perfectly and fulfill their owner's needs.

Moreover this would be hard for people, who have certain disease. For instance, someone has HIV/AIDS, it would be difficult to find a normal job, although we know that HIV/AIDS virus can be transmitted through certain mediums, e.g. sharing needles or syringe for drugs, contact between broken skin, but not from shaking hands or through the air. This would be a discrimination. It also applies to apartment search, the landlord will not give permission easily to the people who have cancer or infectious diseases, they think that it is better to find another healthy people, because they do not want the disease are spread in the room.

The implications of this:

- Connection between health report and tax number gives an opportunity to recognizing people from small community
- Identifying Employee Weaknesses → as a possible consequences: mobbing, blackmail, increased unemployment
- Discrimination by work-community

POSTER SESSION



Alina Khairullina	563009
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Ikhsan Habibi	561046
Julia Rakowiecka	561384
Mert Sevindik	553418

POSTER:

We all worked together on the poster. With the big syringe we wanted to show that our topic was about something medical. On the right hand side next to the syringe you can see a dna helix. We just put it there to specify the medical problem. So, people can directly orientate what is it about. In the syringe we put names and disease like Key:Value pairs in it to show it's about data and we put it in the syringe to demonstrate that this is what our main focus was. The data. All the interpersonal problems we put under the syringe. We wanted to say, if the data comes out of the syringe these problems could happen. On the top left we categorized Actors in passive and active to show that there are two groups. The time was too short to list all the Actors on our poster, but we didn't want to leave it unmentioned that the people who give their data are not active involved in the future of the data.

EVALUATION:

Alina Khairullina:

It was really fun to work with a lot of people who are enough adult, gentle and concentrated to work in a group. We are five people in a group, but we can discuss the situations without any big problems, we are able to find a compromise solution of some problem, so, I liked it. Also the topic of an ethical engineering is interesting and important, and the thing is that, playing some video game or using any software, ethic is sometimes the last thing you think/care about. I am sure, people must pay more attention to that.

Eirene Caroline:

It's nice working with the group of 5, the biggest group I've worked with during Info Labs so far. More people mean more answers, discussions and of course differences. Even though we had different opinions in some cases, but fortunately in the end, we can come up with same answer. From this case I learn that a software engineer must understand the work ethic and relevant law. He must appreciate and avoid harming others, as well as appreciate property rights.

Ikhsan Habibi:

In this exercise, I learned how important to consider the ethical guidelines. Indeed, we need to understand about code ethics in the real life, if we create a software for instance, we need to be able to handle in our case with a proper solution based on ethical guidelines. During the discussion, there were not so many different arguments in our groups. It means, that we agreed with the answers from what we discussed with. Although I had at the beginning some different argumentation, but then I was trying to understand others opinion, it does make more sense with others opinion. What I like about this exercise, we did not just discussed about the case, but there is a fun & creativity part, yap poster session.

Julia Rakowiecka:

One of the main advantage of group work is that it can increase efficiency. I shared ideas with the group and I received feedback. All of the participants were active with discussion, that's why this session was more interesting for me. I can't come up alone with all the solutions and concepts for this project, that's why brainstorming was a great opportunity to show me diverse viewpoints and imaginations of other participants in our team. I learned something interesting about an icelandic population and their culture. During this session I learned also a bit more about an ethical engineering and right now I have better understanding for it.

Taking everything into consideration, it was a great experience. I met new students and I was a part of an international team. My team colleagues shared creative and smart ideas. That way I learned how important is to comply with ethics.

Mert Sevindik:

I found it interesting to read a normal text and think about it's ethical problems as a programmer. After my brain understood how which problems are really important for us and which information is redundant I was very ambitious about finding solutions. We were a group of five people and we all agreed about the problems we saw. So, it was great to work with my group and think about solutions. I guess I really learned to think like a programmer. Not only see interpersonal conflicts. Find a clean, legal and most important scientific solution for a problem.

It was a lot of fun working with my group and I liked the topic. In conclusion I learned to think out of the box and how much fun it is when you have a group where you can agree at some point and everybody brings some skills to present what you want.

TIME

Name	Task	Time	Comment
Alina Khairullina	Lab, Poster, Report	160min	We used Google Docs and literally worked together on everything, so it was brainstorming
Eirene Caroline	Lab, Poster, Report	160min	Everyone in team works together on writing the report.
Ikhsan Habibi	Lab, Poster, Report	180min	We used agile principle, everyone does their own stuff, important is that the report is correctly done.
Julia Rakowiecka	Lab, Poster, Report	180min	We worked together. We shared ideas and corrected our mistakes.
Mert Sevindik	Lab, Poster, Report	160min	Everybody wrote what he wanted in the report and we decided later what we want and not. It worked pretty well for me.