Q&A about the genetic marker analysis of cardiovascular patients project
(*Genmarkøranalyse af hjertekarpatienter*)

1: Which patients will have their genes tested in the project?
A total of 120,000 patients from the Capital Region of Denmark who have been diagnosed with, or treated for, a cardiovascular disease at a hospital within the region from 2009 and onwards.

2: Will all patients who have been diagnosed or treated from 2009 and onwards participate in the project?
No, only some patients will participate.

3: What should I do if I want to know whether my blood sample is part of the project?
You can contact the Department of Clinical Immunology at Rigshospitalet on telephone no. +45 3545 4919, Monday-Friday.

4: What should I do if I don't want to have my genes tested?
If you don't want to participate in the study or in other research projects using blood samples, please register at the registry for use of tissue (Vævsanvendelsesregister). You will then be excluded from the project.
https://sundhedsdatastyrelsen.dk/var (in Danish)

5: What should I do if I want to have my genes tested?
The research project is based on samples already collected, and therefore you cannot register for the project. If you think that you need a genetic examination, please contact your general practitioner.

6: What happens if a congenital disease is discovered in a genetic analysis?
If an unexpected genetic defect is discovered, and the patient is not already familiar with this defect, the project will follow the guidelines from the National Committee on Health Research Ethics. The guidelines state that researchers must react if they find a genetic defect that is very likely to have an impact on the patient’s health and can be cured or treated.
In this case, the patient will be contacted by the hospital department to which he/she is attached, or by a physician from the Department of Clinical Genetics at Rigshospitalet.
See the guidelines here:
http://www.nvk.dk/emner/genomer/vejledning-om-genomer#3.1_Tilbagemelding_til_fors%C3%B8gspersoner (in Danish)
7: Why send the blood samples all the way to Iceland?

deCODE Genetics is one of the world’s largest research centres within genetic analysis and the company has the necessary capacity and experience. Denmark does not have research communities with the same level of experience in large-scale genetic testing.

8: How many people will see my genetic analysis?

When the samples are analysed, it is not possible to see who the individual blood sample comes from. deCode Genetics will work on the blood samples in anonymous form, and Danish researchers will continue their work on the data in anonymous form. Only very few researchers will have access to identify the person.

9: How do you ensure that unauthorised persons cannot access data?

Data will be stored on a secure supercomputer, Computerome, at DTU Risø (Technical University of Denmark), which has been approved to process health data. Among other things, the computer uses Secure Private Cloud ensuring that data remains in the closed system.

10. Who has authorised analysis of the blood samples?

The project was initiated at Rigshospitalet.

The Copenhagen Hospital Biobank, in which the blood samples are stored, has been approved by the Danish Data Protection Agency.

The Danish Data Protection Agency has also approved data handling on Computerome and by deCODE Genetics.

The research project itself has been approved by the National Committee on Health Research Ethics.