

## Gene Coop - Research Plan (2nd Deliverable)

### Questions and Challenges

The open research challenges for the Gene Coop project can be mainly divided in two types:

1. Work together with the stakeholders in order to further define how Gene Coop can best bring benefits for all involved parties, translating therefore the potential of the concept in a concrete application.
2. Implement a technical architecture that serves the Gene Coop purposes and values, based on privacy and user-centric, and open to any party that wants to handle genetic data with respect for user privacy.

Although interrelated, the first point is more social in nature, while the second is more technical.

### **Stakeholders**

The first point consists of creating values for Gene Coop's two main stakeholders, citizens and researchers. Researchers need to be convinced that Gene Coop can provide a means to perform genetic research while letting users in control of their data. An obvious advantage comes from the need to be GDPR compliant, which Gene Coop specifically addresses.

Therefore, concrete research points are:

- How to capture the permissions that a researcher needs to have from a (DNA) data owner in terms of the specific research they want to perform (e.g. using a particular technique and an analysis service, such as Array test with QC and Data curation)
- How to translate these terms in a consent that a user can understand, also clarifying the implications of what the user might agree to.

The latter is very important for citizens, as DNA analysis can reveal a lot of information about a person and their family, possibly about characteristics that either the subject or one of their family members would prefer not to know.

Concrete research points are therefore:

- How to formulate the consent so that it fits a citizen's perspective and possibly that of their family (Is it possible to formulate a consent that can cover enough use cases but at the same time be comprehensible for a user to give?)
- How to find a way to ask citizens for consent when needed without overwhelming them with consent requests.

### **Architecture**

Gene Coop has the ambition of becoming a service that genetic research can use to (legally) operate according to user privacy. The challenge is therefore to design an API interface that is generic enough to be used by different parties, commercial and public ones.

This API interface for DNA analysis activities allows to:

1. specify consent requests

2. verify that consent has been given for a particular operation
3. log operations on the data

Specific research challenges are:

- Gene Coop does not want to store any personal data, but still be able to couple a citizen to their consent, given consent is personal.
- Gene Coop wants to implement a dashboard for citizens to see what has happened with their data, without knowing who the citizen is.
- To increase trust, Gene Coop wants to store consents in a transparent way guaranteeing their integrity. Consents should be anonymous, modifiable and efficiently searchable.

Further, at this stage we are concentrating on a use case with limited number of users. A research challenge is to see whether this approach scales to situations where there are many users, each giving a different consent. Is this still manageable for a researcher to take into account many different constraints on the genetic data they want to analyse?

And finally, we need to investigate whether in the long term some form of consent will require a change in how DNA data is stored, such that we can release only what is needed for a particular use.

## **Research Approach**

Regarding the involvement of stakeholders, we are planning to have co-creation sessions with citizens. We are also actively involving researchers in the project to cover the other stakeholders.

Gene Coop is being developed and tested using a concrete DNA analysis environment called Labspace. Labspace owners (SURF) are involved in the project meetings and the first client for Gene Coop will run in Labspace. This prototype will serve the purpose of clearly understanding the technical implications of what comes out of the stakeholder involvement.

Nevertheless, GeneCoop as a service needs to be designed so that it can become a standard for applications that need user consent. In the long-term we are thinking that GeneCoop might run on top of the European Blockchain Services Infrastructure (EBSI) and use healthcare standards for handling consent such as those FHIR seems to provide. At the moment we therefore need to design and implement so that this perspective is taken into account.

We are looking at integrating identity providers in Gene Coop: researchers use SRAM from SURF, while for users we might implement some SSI service to preserve user privacy. Zenroom could play a role in verifying a particular entity has the right on a particular consent, or needs to view log entries regarding the data they own.

For the storage of consent and logs we are looking at blockchain-based solutions (Sawtooth) as a way to increase trust and transparency.