

# Possible Role of Genetics Clinics in Returning Biobank Results to Donors

**G**enomic and other research data of sample donors are accumulating to the biobanks. Could this data be used to promote the healthcare of the donors?

The EU Horizon 2020 'Genetics Clinic of the Future' (GCOF) project has surveyed the current policies, practices and opinions of European BBMRI-ERIC (Biobanking and Biomolecular Resources Research Infrastructure – European Research Infrastructure Consortium) biobanks on returning biobank results to donors. The aim is to learn from each other's experiences and to gain background knowledge for possible future guidelines.

## We asked European biobanks about returning results

The survey was implemented by using a web-based questionnaire tool (<http://webropol.com>). The data collection of the survey was done in the end of 2015. The questionnaire was sent to European biobanks in 13 countries.

The questionnaire started with questions about national legislation as well as the consent process. The questionnaire then had two sections: the first related to situations where the biobank actively contacts donors offering them (some) results; the second concerned situations where a donor approaches the biobank with the wish to get (some) results from the biobank. The final part of the questionnaire concerned opinions about the possible future role of genetics clinics in these processes.

In total, the questionnaire contained over 30 questions. In this poster we present few selected results.

## Our survey reflects different European practices

The survey succeeded in reaching at least one biobank in all of the 13 countries. Together 72 biobanks replied. The most frequent biobank type was a clinical biobank, and the majority of the respondents identified themselves as biobank directors, heads, managers or similar.

When asked about the policies concerning situations when the biobank approaches the participant to share (some) results, 38 % of the biobanks have a policy to contact participants for sharing results (Fig. 1).

Furthermore, when asked about the policies relating to participants requesting their results from the biobank, almost half of the biobanks replied that they have a policy to return (some) results to the participant (Fig. 2).

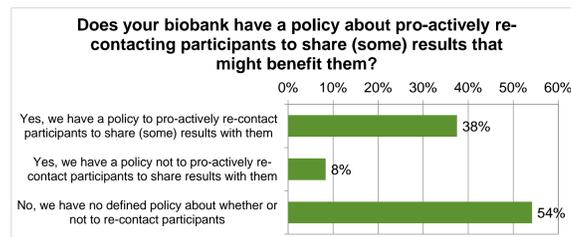


Figure 1. Policies of the biobanks about contacting participants for sharing results. Question no 9 (n=72).

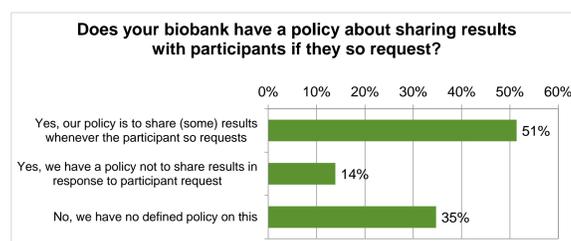


Figure 2. Biobank policies about sharing results with participant's when participants are contacting biobank to request the results. Question no 22 (n=72).

Of the biobanks many have not involved participants, patient organisations or civic organisations in the planning of the policy and the processes of the biobank. However, 1/5 of the biobanks have involved at any rate the patient organisations in the planning (Fig. 3).

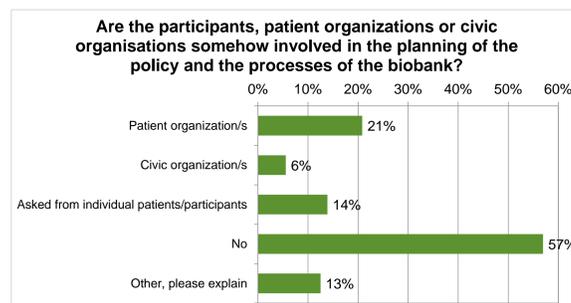


Figure 3. Involvement of participant representatives in the planning of biobank policy and processes. Question 31, multiple choice question (n=72).



Of the respondents 57 % see that biobanks should create a collaboration with genetics clinics for sharing individual results (Fig. 4). However, the majority of the respondents would refer participants to a public clinic, instead of private, for possible treatment and for more information.

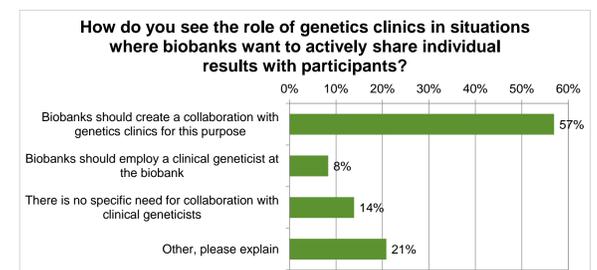


Figure 4. The role of genetics clinics when biobanks want to actively share individual results with participants. Question 33 (n=72).

The majority of the respondents (86 %) believe that individual results from biobanks can benefit the health of the participants.

Read more about the GCOF  
[www.geneticsclinicofthefuture.eu](http://www.geneticsclinicofthefuture.eu)

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## Conclusions

In Europe we do not have an official policy on sharing individual biobank results with donors. The results of this study will help in forming the future guidelines for this purpose.

Traditionally, the majority of referrals to genetics clinics have dealt with rare diseases. In the future, individuals are expected to have growing interest towards their genetic risks and protecting factors relating to common multifactorial diseases as well as their possible carrier status of rare diseases. If also healthy individuals or patients with common disorders will growingly need genetics services in order to understand their biobank results (or direct-to-consumer testing), the resources remaining for the needs of rare diseases may decrease. The GCOF project aims at involving both patients/research subjects and researchers in envisaging the future roles of genetics clinics.