

## COMMENTARY

# A Commentary on For what am I participating? The need for communication after receiving consent from biobanking project participants: experience in Japan

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Organisation for economic co-operation and development defined biobank as a collection of biological material and the associated data and information stored in an organized system, for a population or a large subset of a population. Nowadays, a large-scale biobank is considered an essential resource for research to improve the prevention, diagnosis and treatment of a wide range of illnesses (such as cancer, heart disease, diabetes, dementia and joint problems) and to promote health throughout society. Biobank Japan is the first Japanese nationwide project started in 2003, mainly focused on human genome research aiming to enable personalized medicine. So far, this project seems very productive.

On the other hand, ethical, legal and social issues associated with biobanking have been raised for more than a decade. One of the major issues is that participants are not necessarily fully informed how to use their donated materials as even researchers cannot specify the method to analyze them in the future.<sup>1</sup> Thus, a comprehensive agreement by participants is almost the only choice for future productive research, which makes their autonomous decision difficult.<sup>2</sup> Another important issue is that participant's privacy can never be completely ensured within biobanks.<sup>3</sup> Any elaborate regulations are known not to be able to prevent private information leaking because of carelessness. Despite of these issues, people repeatedly joined the research with trust such as 'data should be used properly' or 'data will be beneficial to patients in the future.' In fact in our experi-

ence, participants often express their feeling saying 'I don't understand difficult thing, but I'll participate if it's useful.'

In the previous issue of the *Journal of Human Genetics*, Muto *et al.*<sup>4</sup> study participant's understanding who supposed to have fully IC process at the time of joining the Biobank Japan Project (BBJP). They found that participants often misunderstand or forget the information provided during IC process including the objective of the project and non-disclosure policy of personal analyzed results. This indicates that IC in an initial recruit period is far less sufficient to maintain participants' understanding of the project, meaning continuous communication is mandatory throughout the project. To overcome this issue, the authors organized four types of communication methods; public forums, website, newsletter and direct contact. They suggested that using all four methods coordinated properly would make communication effective as each method has its own limitation(s) in terms of accessibility and interactivity. For example, newsletter is a basically one-way approach but have a merit to reach participants equally. In their study, comments like 'contents are too difficult to follow' and 'too much volume of text' were obtained. Previous studies have indicated that excessive amount of information in a long sheet could degrade participants' understanding, and quantity, quality and formatting of the information must reflect the interests and competencies of participants.<sup>5</sup> This may be a key consideration for newsletters to medically-naïve or illiterate people. Furthermore, annual face-to-face meeting of participants with medical coordinator who collect participants' blood sample seems to be a good chance for interactive communications. This could be also a

learn participants' response and to maintain a sense of trust with them. Anyway, efforts of continuous communication with participants would be extremely important not only to promote the project properly, but also to obtain social recognition of the research. We believe that this could be also a countermeasure for a part of the ethical, legal and social issues pointed out above. In this sense, development and evaluation of effective method of communication with participants would be an essential research theme to face a personal genome era.

In Japan, other government funded large-scale cohort studies such as Japan Environment and Children's Study launched in 2010 (ref. 6), genome-cohort project supposed to start in 2013 (ref. 7) succeeded BBJP. Maintaining participants' trust would be undoubtedly essential for all these projects, and the experience of communication methods in BBJP described in this article would be valuable.

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