

“NO FURTHER USE” withdrawal option – UK Biobank’s commitment to your wishes

The UK Biobank Ethics & Governance Framework and the UK Biobank participant information leaflets (Information Leaflet and Further Information Leaflet) guarantee that there will be no further use of participants’ samples and data if they choose the ‘No further use’ option for withdrawal from the project.

UK Biobank is completely committed to this obligation and to ensuring that participants are fully informed about important developments with the project.

One such development to emerge during the establishment of the project’s IT systems is that, although data from participants can be made unusable, it is not possible to destroy it completely. This is due to the development of complex IT systems designed to protect the integrity and security of those people who have taken part.

While we can absolutely guarantee that data from participants who choose the ‘No further use’ withdrawal option will cease to be used for any research purpose, it cannot be deleted entirely from UK Biobank records.

As before, all blood and urine samples will be destroyed if a participant chooses the ‘No further use’ withdrawal option (although as made clear in the participant information literature, it may not be possible to trace all distributed sample remnants).

The reasons for this change have been discussed, and agreed, with the Ethics & Governance Council. UK Biobank believes it is important that this change to the ‘No further use’ option of withdrawal be publicised.

Changes have also been made to the relevant section of our Ethics & Governance Framework and to the information materials. So, for example, the Information Leaflet now reads:

“No further use: This means that, in addition to no longer contacting you or obtaining further information about you, any information and samples collected previously would no longer be available to researchers. UK Biobank would destroy your samples (although it may not be possible to trace all distributed sample remnants) and would only hold your information for archival and audit purposes. Your signed consent and withdrawal would be kept as a record of your wishes. Such a withdrawal would prevent information about you from contributing to further analyses, but it would not be possible to remove your data from analyses that had already been done.”