

UK Biobank Showcase

Documentation on the lost-to-follow-up variable

The “lost to follow-up” variable has been created by amalgamating data from several sources, indicating that UK Biobank has stopped receiving follow-up data for a participant. It is available in the UK Biobank Showcase as two data-fields:

- Field 190: Reason lost to follow-up
- Field 191: Date lost to follow-up

Field 190 can take 5 possible values, reflecting the various events that are currently considered to mean that a participant has been lost to follow-up:

Coding	Meaning
1	Death reported to UK Biobank by a relative
2	NHS records indicate they are lost to follow-up
3	NHS records indicate they have left the UK
4	UK Biobank sources report they have left the UK
5	Participant has withdrawn consent for future linkage

Note that for participants with multiple loss-to-follow-up events (e.g., emigrating and then withdrawing from the study), only the earliest event is recorded.

1. Death reported to UK Biobank by a relative

These are cases in which a relative has called the UK Biobank Participant Resource Centre (UKB-PRC) to notify that a participant had died, without UK Biobank having received an official death certificate from the Death Registry.

2. NHS records indicate they are lost to follow-up

These are participants for whom the National Health Service (NHS) has notified UK Biobank that it had lost the ability to link to their clinical data.

3. NHS records indicate they have left the UK

These are participants for whom the NHS has notified UK Biobank that they had left the United Kingdom, meaning that their future health records are no longer accessible.

4. UK Biobank sources report they have left the UK

These are participants who have called the UKB-PRC to notify us that they are moving overseas, meaning that their future health records are no longer accessible.

5. Participant has withdrawn consent for future linkage

These are participants who have asked UK Biobank to no longer contact them or obtain information from their health-related records. However, UK Biobank still has permission to use their clinical information and samples collected previously.