# Additional notes on Ethics

This research was designed in accordance with ethical guidelines outlined by the Market Research Society and ESOMAR[[1]](#footnote-1), while following General Data Protection Regulation guidelines from the Information Commissioner's Office. It was developed under the supervision of the Wellcome project team, but did not go through a formal ethical approval process.

This research operated using an ongoing model of informed consent, where respondents could revoke their participation and ask to remove their data from the project at any time. Interviewees were informed about the nature of the project when first contacted, before filling in an expression of interest form. Once they consented to taking part by filling in the form, those selected for interview were also informed about the project and their rights as participants in the confirmation email and again by their interviewers before the interview start, after which respondents were asked to verbally consent. Survey respondents were informed about the nature of the project and what was involved in participation when they were sent the survey invitation email as well as on the survey landing page.

All participants were informed from first contact that the project was run on behalf of Wellcome, who would have access to all anonymised findings, but the data collection and analysis was carried out by an independent research agency – Shift Learning. Interviewers did not discuss or report their own bias, assumptions, personal interest in the topic, involvement in the research environment or demographics with interviewees. Interviewees were incentivised with a £60 cheque for taking part. Survey participants were incentivised with entry into a £350 prize draw. Everyone approached to take part in this study was provided with options to opt out of any further contact and communication about it.

In line with these guidelines, and due to potentially difficult personal experiences that might have been discussed, interviewees were assured of their confidentiality and informed that findings would be anonymised by removing any clear identifiers. Phone interviews were audio recorded for transcription purposes. Audio files were stored securely on password-protected drives by Shift Learning, handled according to their retention policy (aligned with GDPR requirements) and then deleted at the project close. Full interview transcriptions were deleted once anonymised, while anonymised transcripts will be retained for one year from project close, for audit purposes. Respondents were able to receive their transcript and redact or comment on their responses. They were also offered an option to remove sensitive sections from the transcript so they were decontextualized from the rest of the interview. Transcripts will not be made available under open-access rules, due to confidentiality concerns. Survey respondents were guaranteed anonymity, therefore published quantitative data will not include open responses, nor possibly identifying demographic information.

1. European Society for Opinion and Marketing Research [↑](#footnote-ref-1)