

Qualtrics survey that includes sensitive data and questionnaires.

In the past, it was not allowed to set up sensitive data and questionnaires in one survey.

In the current Qualtrics environment, it is now possible to set up both sensitive data (e.g. name, address, telephone number Social Security (BSN) number (only for Dutch people), etc.) including the studies' questionnaire(s) in one survey. If you want to set up this type of survey there are a few important details you have to take into account:

- Be aware that the collected data is not anonymous and should be kept in the "P-folder" (Privacy-folder) in your RDM environment. Therefore, also request for a "P-folder" from Data management.
- As soon as all data has been collected, download the collected data from Qualtrics, save them in your RDM-P-folder and delete all collected data from Qualtrics.
- The survey cannot be stored in the RDM-folder "Raw data" until all sensitive data has been removed from the dataset. In other words, you need to pseudonymize the data set by separating the sensitive data-> save in "P-folder" (if still needed or delete them) from the data set-> save in "Raw Data" folder.
- Check also the rules for Personal data below.

Rules for Personal data:

- Personal data should be stored 'Confidentially'. This means storage in a secure environment accessible only to a limited number of people, typically the investigator(s) or co-investigator(s). For this, RDM provides a 'Privacy' folder on their data server.
- Personal data may not be kept longer than is necessary for the ongoing study. Yet, this can be quite long: RDM requires that raw data (e.g. completed questionnaires, scoring lists, recorded audio, MRI, EEG), Personal or not, must be kept for at least 10 years after the last publication. An exception to this rule is when participants have given approval for their Personal data to be retained for a longer period of time and for a clearly defined purpose - follow-up studies, for example.
- Collect no more Personal data than strictly necessary.
- Publication of data is possible if the data are not in any way linked to specific participants anymore and are therefore anonymous. This means that also the key file no longer exists. In addition, aggregated data can be published. If you wish to make other datasets available in light of open science, the data needs to be pseudonymized and a data transfer agreement needs to be drafted by our privacy team.

For questions concerning privacy and personal data, contact privacy-fpn@maastrichtuniversity.nl