Checklist information form: which information do you need to provide to the data subjects if you process personal data that is not directly collected from them?

If you process personal data that is not collected directly from the data subject themselves because you use secondary data, for example from a previous research project or that you obtained from another research or government institution, you must also inform the data subject of this. It is important to provide this information within a reasonable period of time (e.g. when obtaining the data, at first contact with the data subject, when the data are first disclosed).

In the case of secondary processing, you should not provide this information if the data subject already has the information or if the provision of the information would require a disproportionate amount of effort, or the achievement of the purposes of the processing is likely to be impossible or seriously compromised. threatens to compromise. If you use one of these two exceptions for your research, you must always take appropriate technical and organizational measures such as pseudonymizing the data. In addition, you must motivate / document this exception in the GDPR register of UGent.

To correctly inform those involved, you must provide them with the following information:

☐ From which **source** the personal data comes

➔ If applicable, you must also state **the public source** where the personal data comes from

☐ **What information** you will collect

➔ Give a (general) overview of the personal data or types of personal data that will be collected
➔ Please note: if you are processing special categories of personal data, you must clearly state this and give an overview of the special categories of personal data that you will process

☐ What the **purpose** and **legal ground** of the processing is

➔ Why are the personal data processed?
  - Describe the research purpose. Provide sufficient information, in layman's language, so that the participant understands what the research is about and what is expected of him / her

➔ What does participation in the study entail?
  - Procedures / type of research intervention
  - Expected duration of the participation
  - Possible disadvantages / consequences / risks for the participant
  - Possible benefits for the participant
  - Possible reimbursements (eg travel expenses)
  - If applicable: approval of the ethics committee

➔ What is the legal ground of the personal data processing?
  - Consent of the data subjects
    - Inform the data subjects of their right to withdraw their consent to the processing of their personal data at all times and explain how they can do this
    - If you process personal data on the legal ground of consent, then make sure that the information on your information form matches with the information you give in the consent form!
  - Necessary for the performance of a task in the public interest

        - !This legal ground requires a reference to EU or Member State law where this task of public interest has been determined
    - The legitimate interest of the controller or of a third party
        - This legal ground requires a balancing of interests between the legitimate interest of the controller (eg UGent) and the interests of the persons whose data are processed (data subjects)
    - Legal or contractual obligation or necessary condition to conclude an agreement
        - Is the data subject obliged to provide data?
        - Possible consequences if the information is not provided

➔ Is automated decision making (incl. profiling) involved?

☐ What the **duration of the processing** and the **retention period** is

➔ What is the duration of the research and what will happen to the data afterwards (eg will the data be shared with other researchers afterwards, will a publication follow, etc.)?

➔ How long will the data be stored?

☐ Who has **access** to the data during and after the research (access is also seen as sharing data during and after your research)

➔ Which persons (eg researchers or employees) have access to the data during and after the research?

➔ For what purpose?

➔ Will the data be transferred to or shared with third parties during or after the research?

- If yes: inside / outside the research group, inside / outside UGent?
- If yes: inside / outside the EU?

☐ How is the **confidentiality** of the personal data guaranteed?

➔ Which measures are applied to protect the personal information about the participants (eg secure storage, encryption, pseudonymization, etc.)?

☐ What **rights** the data subjects have and how they can exercise them

➔ Are the data subjects informed about their rights?

- With a few exceptions, the data subjects have the following right: right to be informed, right of access, right of rectification, right to be forgotten, right to limit the processing, right to data portability.

➔ Are the data subjects informed about how they can exercise these rights?

- via the researcher(s) involved (add contact details) and / or via the UGent Data Protection Officer (privacy@ugent.be, T 09 264 95 17)

➔ Are the data subjects informed about the possibility of submitting a complaint to the Supervisory Authority?

- Gegevensbeschermingsautoriteit, Drukpersstraat 35, 1000 Brussel. contact@apd-gba.be

☐ Whether all rights of the data subjects are respected and whether the possible **exceptions** for research have been checked / substantiated

➔ See research tip https://onderzoektips.ugent.be/en/tips/00001790/

➔ State any exceptions

☐ Who is **responsible** for the processing of personal data

➔ Contact details of the data controller (or a representative thereof / the researcher)

➔ Contact details of the UGent Data Protection Officer (privacy@ugent.be, T 09 264 95 17)