Information to be provided where personal data have not been obtained from the data subject

In most studies, it is possible to inform subjects directly about the processing of any of their personal data. However, there are also studies in which informing the subject directly is not as straightforward (e.g. in social media research). The purpose of this guide is to show you what steps you should follow in these situations.

Even if your data subjects do not actively participate in your research project, it is important to be transparent to your data subjects in case you process their personal data. The GDPR art. 13 and art. 14 include a list of points that you need to provide 'to the data subject in a concise, transparent, intelligible and easily accessible form, using clear and plain language' (art. 12(1)). If it is not possible to inform the data subjects directly or it would involve a disproportionate effort (the number of data subjects, the age of the data and any appropriate safeguards adopted should be taken into consideration, rec. 62), then you have to take appropriate measures to protect the data subject's rights, freedoms, and legitimate interests. This may include making the following information publicly available within one month after the start of data collection (e.g. via a website: contact the DCC for further advice).

Research information & data management

- a) Inform the data subjects about the purposes of the processing for which the personal data are intended as well as the legal basis for the processing; Note: In this research scenario, the legal basis for processing personal data is public interest. It is important that the P&S coordinator has confirmed the use of public interest as a legal ground and that the ethics board of your faculty has reviewed your study design from an ethical perspective.
- b) Inform the data subjects about the personal data that you process, and whether these include special categories of personal data;

 Note: Check the DCC website for more information on personal data and special categories of personal data.
- c) Inform the data subjects about the recipients or categories of recipients of the personal data, if any;

Note: Recipients or categories of recipients are the recipients who will have access to the personal data within your organization, the external organizations who have access to the personal data, and the recipients within this external organization who will have access to the personal data.

- d) Where applicable, inform the data subjects about the fact that you intend to transfer personal data to a third country or international organization and of the existence or absence of an <u>adequacy decision</u> by the European Commission. If you would like to transfer personal data to a third party that fits these criteria, please consult the <u>Privacy & Security coordinator</u> of your faculty beforehand;
- e) Inform the data subjects about the source of origin of the personal data and, if applicable, whether it came from publicly accessible sources;
- f) Inform the data subjects about the period for which the personal data will be stored;

Note: Use the data management policy of the university and the data management protocol of your faculty as a guideline for how long you should store your data (<u>DCC website</u>).

g) Where applicable, inform the data subjects about the existence of automated decision-making that could affect their personal life (see example). This should include meaningful information about the logic involved, as well as the significance and the envisaged consequences of such processing for the data subject.

Note: most research does not involve automated decision-making that can affect the personal life of the data subjects. Do you think you are using automated decision-making that impacts your data subjects' personal life? A <u>Data Protection Impact Assessment</u> is mandatory. Please contact <u>the DCC</u> or the <u>P&S coordinator</u> of your faculty for advice.

Rights of the data subject

Inform the data subjects about the existence of the rights of data subjects to request access to and rectification or erasure of their data and to object to the processing of their data;

Note: Data subjects have the right to access, rectification, and erasure of their personal data. Explain until when, and how, participants can ask for a copy of their personal data, have erroneous personal data corrected, and have their personal data withdrawn. There are exceptions for scientific research (art. 89-2). If you are using these exceptions, then you should inform your data subjects about this and explain why these exceptions are necessary for the research purpose.

Contact information

a) Provide the identity and the contact details of the <u>controller</u> (e.g. University of Groningen) and, where applicable, of the controller's representative; and the contact details of the data protection officer:

If you have any questions or requests regarding the processing of your personal data, please contact:

University of Groningen

Postal address: P.O. Box 72, 9700 AB Groningen, the Netherlands

for the attention of the Central Privacy Desk

E-mail: privacy@rug.nl

Your message will always be shared with the Data Protection Officer (DPO) of the UG.

b) Provide information on the right to lodge a complaint with a supervisory authority as well as the contact details of this authority. If the controller of the personal data is based in the Netherlands, the supervisory authority is the <u>Autoriteit Persoonsgegevens</u>.