Is my research project subject to notification?
Privacy is a fundamental right, which safeguards the respect for private life without coercion or interference from the government or other people.

This principle is anchored in the European Convention on Human Rights and also in the Norwegian Constitution.

Privacy refers not only to the protection of privacy and the individual's personal integrity. A Norwegian understanding involves the concept also largely protected by individual right to influence the use and dissemination of personal information about themselves. Individuals must as far as possible be able to decide over their own personal data.
ACTS OF LEGISLATION RELATED TO RESEARCH AND PRIVACY

Act on ethics and integrity in research (Forskningsetikkloven)
Personal Data Act (Personopplysningsloven)
Health Research Act (Helseforskningsloven)

IMPORTANT INSTITUTIONS

NSD – Data Protection Official for Research
http://www.nsd.uib.no/personvern/en

Regional Committee for Medical and Health Research Ethics (REC)
https://helseforskning.etikkom.no

The Norwegian Data Protection Authority (Datatilsynet)
https://datatilsynet.no/English/
WHEN DOES THE NOTIFICATION OBLIGATION APPLY?

Your project is subject to notification if you plan to process personal data using:

- computer-based equipment like text, audio or video files, USB, smartphone, and/or
- manual storing of sensitive data sorted by name or personal identification number.

Note that you have an obligation to notify even if an individual remains anonymous in publications from the project. The main issue is how personal data is processed during the whole project; from collecting data until results are published.
COLLECTING DATA ABROAD?

If you are a student/researcher at an institution in Norway, you are required to notify The Data Protection Official for Research (NSD) when processing personal data in the same way as for data collection in Norway!
WHAT IS PERSONAL DATA?

Any information that may be linked to a person is considered personal data. The information may be linked to a person in any of the following ways:

- **directly** through name, personal identification number, or other unique personal characteristics

- by being traceable to an e-mail or IP address (e.g. online surveys)

- **indirectly** through a combination of background information such as place of residence or institutional affiliation, combined with data on age, gender, occupation, diagnosis, etc.

- through a number referring to a list of names
WHAT IS SENSITIVE PERSONAL DATA?

Sensitive personal data are data about:

- racial or ethnic background
- political, philosophical or religious views
- a person suspected, charged, prosecuted or sentenced for a criminal offence
- health issues
- membership in trade unions

Will the data contain sensitive personal data? If so, your project may be subject to notification even if the information is not processed on a computer. If the personal data is systematically stored so that information concerning an individual may be retrieved, then the project is subject to notification.
CHILDREN

Depending on the project, common practice is an age limit of 15 to give consent, and 16-18 when gathering sensitive personal data.

If the children is under 16 both the parent and children have to give an informed consent.
HOW CAN A PROJECT BE CARRIED OUT WITHOUT BEING SUBJECT TO NOTIFICATION?

For a project not to be subject to notification, all electronic data processed through the entire research process has to be anonymous. In addition, no sensitive data can be linked to directly identifiable personal data, nor via code or reference number referring to a separate list of names.

Data from records and registries can be used without making a notification as long as only anonymous data is extracted. (e.g. SSB, NSD)
If your project is subject to notification, you have to submit a notification form no later than 30 days prior to the processing of personal data, and feedback from the Data Protection Official must be awaited before the project can be commenced.


TEST: http://www.nsd.uib.no/personvern/en/notification_duty/test
REQUIREMENTS FOR INFORMED CONSENT

In order to define a consent as valid, the consent must be a freely given, specific and informed declaration. This entails that the person requested to participate in the research project must understand what the consent is concerning and what the consequences of participation will be. It is common to formulate an information letter that includes an inquiry regarding participation and information about the project.

NSD have an example of an information letter on their web-page: