NOTIFICATION FORM (ENGLISH TRANSLATION) – NSD

NB! This translation is to be used as an aid when filling in the online Notification Form (currently only in Norwegian)

- Personal data
- Types of data
- Project Information
- Responsibility
- Sample and Criteria
- Third Persons
- Documentation
- Other approvals
- Processing
- Information Security
- Duration of project
- Additional Information
- Send in

Which personal data will be processed?

Personal data are any data about an identified or identifiable natural person (data subject). Pseudonymised data are also considered personal data.

“Pseudonymisation” means processing collected data in way that the data can no longer be linked to individual persons, without the use of additional information. This usually involves removing identifiable information such as name, national ID number, contact details etc. from the collected data and giving each data subject a code/number. A scrambling key is the file/list of names and codes that makes it possible to identify individuals in the collected data. The scrambling key should be stored separately form the rest of the data. NB: processing pseudonymised data is still considered processing personal data, even if you do not have access to the scrambling key, and even if the scrambling key is being stored by an external party, such as SSB, the National registry etc.

Name (also with signature/consent)
First name and surname
☐ Yes ☐ No

National ID number or other personal identification number
11-digit personal identifier, D number, or other national identification number
☐ Yes ☐ No

Date of birth
☐ Yes ☐ No
Address or telephone number
- Yes
- No

Email address, IP address or other online identifier
An email address is a unique address that is assigned to the user of an electronic mail service. An IP address is a unique address that is assigned to a device (e.g. a computer) in a computer network like the Internet. Dynamic IP addresses may also be considered personal data in certain cases. Cookies are an example of an online identifier. NB! If you are going use an online survey, and the service provider (data processor) will have access to email addresses or IP addresses, you must indicate this here.
- Yes
- No

Photographs or video recordings of persons
Photographs and video recordings of faces are usually considered to be personal data.
- Yes
- No

Audio recordings of persons
Audio recordings where personal data are recorded and/or where there exists a scrambling key that links the audio recordings to individual persons on the recordings. The voice of the person speaking is considered personal data in itself.
- Yes
- No

GPS data or other geolocation data
Data which indicate the geographical location of a person.
- Yes
- No

Background data that can identify a person
E.g. a combination of information such as municipality of residence, workplace, position, age, gender etc.
- Yes
- No

Genetic data
Personal data relating to the inherited or acquired genetic characteristics of a natural person, which give unique information about the physiology or health of that person.
- Yes
- No

Biometric data
E.g. fingerprint, handprint, facial form, retina and iris scan, voice recognition, DNA.
- Yes
- No
Other data that can identify a person
If you think that you will be processing personal data but cannot find a suitable alternative above, indicate this here.

☐ Yes  ☐ No

Next

Which background data that can identify persons will you be processing? (if applicable)

Which other data that can identify persons will you be processing? (if applicable)

Will special categories of personal data or personal data relating to criminal convictions and offences be processed?

Racial or ethnic origin
This includes belonging to an ethnic group, population, cultural sphere or society that has common characteristics. For example, information that a person is Sami is not considered to say anything about race but it says something about ethnicity.

☐ Yes  ☐ No

Political opinions
That a person is a member of a political party and/or what a person voted in an election, including political opinions and beliefs. However, this does not include information that a person is a conservative, radical or labour party supporter.

☐ Yes  ☐ No

Religious beliefs
That a person is a member of a religious organisation/congregation. This does not include information that a person has a subscription to a religious newspaper.

☐ Yes  ☐ No

Philosophical beliefs
That a person is a member of a philosophical association, or that a person believes that knowledge is acquired through logical speculation and observation.

☐ Yes  ☐ No
Trade Union Membership
That a person is a member of a trade union that organises employees within the same industry/subject area, e.g. LO, NTL, NAR etc.
☐ Yes ☐ No

Health data
Personal data concerning a natural person’s physical or mental health, including use of healthcare services.
☐ Yes ☐ No

Sex life or sexual orientation
A person’s sexual orientation (homosexual, lesbian, bisexual etc.) and/or sexual behaviour (e.g. that a personal has been unfaithful, indecent exposure, offensive gestures/language)
☐ Yes ☐ No

Criminal convictions and offences
Personal data concerning convictions and offences, or related to security measures.
☐ Yes ☐ No

Project Information

Edit project  + Register new project  Chose existing project

if ‘Register new project’:

Title
The title must describe the content of the project

Project description
Give a description of the project’s scientific purpose/research question

Subject area
☐ Humanities
☐ Social sciences
☐ Mathematics and natural sciences
☐ Technological sciences
☐ Medical sciences
☐ Agriculture and fisheries
Will the collected personal data be used for other purposes, in addition to the purpose of this project?

Personal data should only be processed for specified, explicit and legitimate purposes. This means that each purpose for processing personal data must be identified and described clearly and accurately. In order for a purpose to be considered legitimate, it must also be in accordance with ethical and legal norms.

Explain why it is necessary to process personal data.

Explain why the personal data are adequate, relevant and limited to what is necessary for the purposes for which they are being processed. This includes limiting the amount of collected data to that which is necessary to realise the purposes of data collection.

Project description

External funding

The Research Council of Norway (Norges forskningsråd - NFR)

Public authorities  E.g. research commissioned by a ministry

Other  E.g. funding from a pharmaceutical company or from private actors

Type of project

Research Project and PhD thesis

Student project, Master’s thesis

Student project, Bachelor’s thesis

Other student project
Contact information, student (if student project)

Name

E-mail

Telephone number

Next

Responsibility for data processing

Data controller
The institution responsible for the processing of personal data. The data controller determines the purposes for which, and the manner in which, personal data are processed.

Project leader (research assistant/ supervisor or research fellow/phD candidate)
The person responsible for the project.

Name

Position

Email address

Telephone number

Will the responsibility for processing personal data be shared with other institutions (joint data controllers)?

Yes  No

If two or more institutions together decide the purposes for which personal data are processed, they are joint data controllers.

Joint data controllers (if applicable)

Institution

Institution not found in the list

Institution

Country

Postal address
Whose personal data will be processed?

You must describe each group of people whose personal data you will be processing. Add and describe each sample individually.

+ Add sample

Sample 1

Describe the sample

Recruitment or selection of the sample
Describe how the sample will be recruited and how initial contact with the sample will be made. For example, whether you will make initial contact during field-work or via your own network, or whether a school, hospital or organisation will contact its pupils, patients or members on your behalf. If the sample will not be recruited but will be selected from a registry or an administrative system etc., describe how the selection will be carried out and what the selection criteria will be.

Age

years (to) years

Will you include adults (18 år +) who do not have the capacity to consent?

i.e. the person has reduced capacity or lacks capacity to consent. For example, the person may have mental/cognitive impairment, significant physical/emotional ailments, or may be unconscious, conditions which make it difficult or impossible for the person to gain sufficient understanding in order to give valid consent. The central aspect is whether the person is capable of understanding the purpose of the processing/project in question, and of understanding potential positive and negative consequences (immediate and long-term).

Yes  No

Explain why it is necessary to include adults who do not have the capacity to consent (if applicable)
Personal data for sample 1

Here you will see all the types of personal data which you selected on the first two pages of the form; «Personal data» and «Types of data». Select the types of personal data that are correct for sample 1. If all types of data shown below are correct, select all of them.

Name
National ID number or other personal identification number
Date of birth
Address or telephone number
Email address, IP address or other online identifier
Photographs or video recordings of persons
Audio recordings of persons
GPS data or other geolocation data
Demographic data that can identify a natural person
Genetic data
Biometric data
Other data that can identify a natural person

How will you collect data from sample 1?

Here you must add each method/source of data that will be used for data collection

Personal interview
Group interview
Online survey
Paper-based survey
Participant observation
Non-participant observation
Field experiment / field intervention
Web-based experiment
Tests for pedagogical research / psychological tests
Medical examination and/or physical tests
Human biological material
Social media – open forum
Social media – closed forum
Discussion board/forum for online newspapers/online debates
Big data
Medical records
Biobank
Data from another research project
Other
Statistics Norway - SSB
Criminal records (Det sentrale straffe- og politiopplysningsregisteret, SSP)
Medical Birth Registry of Norway (Medisinsk fødselsregister, MFR)
Norwegian Registry of Pregnancy Termination (Register over svangerskapsavbrudd)
Norwegian Cardiovascular Disease Registry (Hjerte- og karregisteret)
Norwegian Cause of Death Registry (Dødsarsaksregisteret, DÅR)
Norwegian Prescription Database - NorPD (Reseptregisteret)
Norwegian Immunisation Registry (Nasjonalt vaksinasjonsregister, SYSVAK)
Norwegian Surveillance System for Communicable Diseases (Meldesystem for smittsomme sykdommer, MSIS)
Norwegian Surveillance System for use of antibiotics and healthcare related infections (Norsk overvåkingssystem for antibiotikabruk og helsetjenesteassosierde infeksjoner, NOIS)
Norwegian Surveillance System for Antimicrobial Drug Resistance (Norsk overvåkingssystem for antibiotikaresistens hos mikrober, NORM)
Norwegian Surveillance System for Virus Resistance (Norwegian Surveillance System for Virus Resistance, RAVN)
Norwegian Patient Registry (Norsk pasientregister, NPR)
IPLOS-registeret
Kommunalt pasient- og brukerregister (KPR)
Cancer registry of Norway (Kreftregisteret)
Genetic Mass Survey of Newborns (Genetisk masseundersøkelse av nyfødte)
Reseptformidleren
Forsvarets helseregister
Helsearkivregisteret
Helseundersøkelsen i Nord Trøndelag (HUNT)
Tromsø-undersøkelsen
SAMINOR
Den norske mor og barn undersøkelsen (MoBa)
Nasjonalt register for langtids mekanisk ventilasjon
Nasjonalt kvalitetsregister for barnekreft
Norsk Kvalitetsregister Øre-Nese-Hals–Tonsilleregisteret
Norsk vaskulittregister & biobank (NorVas)
Norsk Parkinsonregister & biobank
Norsk karkirurgisk register (NORKAR)
Norsk hjertinfarkregister
Gastronet
Norsk register for analinkontinens
Nasjonalt barnehofsteregister
Norsk kvalitetsregister for artrittsykdommer (NorArtritt)
Norsk nakke- og rygregister
Nasjonalt korsbåndregister
Nasjonalt register for leddproteser
NorKog
Norsk MS-register og biobank
Nasjonalt register for KOLS
Nasjonalt kvalitetsregister for lymfom og lymfoide leukemier
Nasjonalt kvalitetsregister for lungekreft
Nasjonalt kvalitetsregister for følekreft
Nasjonalt kvalitetsregister for brystkreft
Nasjonalt kvalitetsregister for prostatakreft
Nasjonalt kvalitetsregister for tykk- og endetarmskreft
Nasjonalt register for ablasjonsbehandling og elektrofysiologi i Norge (ABLA NOR)
Norsk register for invasiv kardiologi (NORIC)
Norsk hjertesviktregister
Norsk pacemaker- og ICD-register
Nasjonalt kvalitetsregister for gynekologisk kreft
Norsk register for gastrokirurgi (NoRGast)
Nasjonalt kvalitetsregister for behandling av spiseforstyrrelser (NorSpis)
Legal basis for processing personal data

- Consent (art. 6 nr. 1 a)
- Performance of a contract (art. 6 nr. 1 c)
- Performance of a task in the public interest (art. 6 nr. 1 e)
- Purposes of legitimate interests (art. 6 nr. 1 f)

Legal basis for processing special categories of personal data (if applicable)

- Explicit consent (art. 9 nr. 2 a)
- Data which are manifestly made public by the data subject (art. 9 nr. 2 e)
- Purposes of preventative or occupational medicine (art. 9 nr. 2 h)
- Archiving purposes in the public interest, scientific or historical research purposes, or statistical purposes (art. 9 nr. 2 j)
- The data source does not include special categories of personal data

Who will give consent on behalf of children under 16 years? (if applicable)

- Parent/guardian
- Child

Who will give consent on behalf of youths 16-17 years? (if applicable)

- Parent/guardian
- Youth

Information for sample 1

Will you inform the sample about processing their personal data?

- Yes
- No

How?

- Written information (on paper or electronically)
- Oral information

Note that the requirements for what you have to give information about have changes with the new legislation (20 July 2018). Check out our template for the information letter to make sure that you include all obligatory information.
Will you inform the sample about processing their personal data?

- [ ] Yes
- [x] No

Explain why the sample will not be informed about the processing of their personal data (if applicable)

Will persons who do not have the capacity to consent receive specially adapted information? (if applicable)

- [ ] Yes
- [x] No

Describe the third persons

Types of personal data about third persons

- Name
- National ID number or other personal identification number
- Date of birth
Address or telephone number
Email address, IP address or other online identifier
Photographs or video recordings of persons
Audio recordings of persons
GPS data or other geolocation data
Demographic data that can identify a natural person
Genetic data
Biometric data
Other data that can identify a natural person

Which sample will provide information about third persons?
- [ ] Sample 1
- [x] Sample 2 etc.

Will third persons consent to the processing of their personal data?
- [ ] Yes
- [ ] No

Will third persons receive information about the processing of their personal data?
- [x] Yes
- [ ] No

Upload information letter
Chose file...

Will third persons receive information about the processing of their personal data?
- [ ] Yes
- [x] No

Explain why third persons will not be informed (if applicable)

Next

**Documentation**

How will consent be documented? (if applicable)
- [x] Electronically (e-mail, e-form, digital signature)
- [ ] Manually (on paper)
- [ ] Orally
The law does not set requirements as to whether consent must be given in writing or verbally, but you must be able to document that consent has been obtained. Oral consent can be documented with the use of a sound recording.

Describe (if applicable)

How can consent be withdrawn? (if applicable)

Total number of data subjects in the project

(Data subjects= persons whose personal data you will be processing)

- 1-99
- 100-999
- 1000-4999
- 5000-9999
- 10,000-49,999
- 50,000-100,000
- 100,000+

How can data subjects get access to their personal data or how they can have their personal data corrected or deleted?

Rights of data subjects (participants) include the right to access one’s own personal data and to receive a copy of one’s data if asked for. A data subject can request that their personal data are corrected if they feel that the information is wrong or lacking, and the data subject can withdraw consent and request that their personal data are deleted. Give a short description of the procedure for how a data subject can get access to their personal data, and how they can have their personal data corrected or deleted.

Next
Other approvals

Will you obtain any of the following approvals or permits for the project?
Indicate if you will obtain any of the following approvals or permits in order carry out the project.

- Ethical approval from The Regional Committees for Medical and Health Research Ethics (REC)
- Confidentiality permit (exemption from the duty of confidentiality) from the Regional Committees for Medical and Health Research Ethics (REC)
  REC has the authority to grant a confidentiality permit for the processing of health data, both for health research and other research.
- Approval from own management for internal quality-assurance and evaluation of health services (intern kvalitetssikring) (The Health Personnel Act § 26)
- Confidentiality permit (exemption from the duty of confidentiality) from the Norwegian Directorate of Health, for quality-assurance and evaluation of health services (kvalitetssikring) (The Health Personnel Act § 29b)
- Biobank
- Confidentiality permit (exemption from the duty of confidentiality) from Statistics Norway (SSB)
  Statistics Norway has the authority to grant a confidentiality permit for the data that they manage, e.g. data about population, education, employment and social security.
- Approval from The Norwegian Medicines Agency (Statens legemiddelverk, SLV)
  E.g. for a clinical drugs trial
- Confidentiality permit (exemption from the duty of confidentiality) from a department or directorate
- Other approval
  E.g. from a Data Protection Officer

Indicate which approval

Upload document (‘oppdragsdokument’)
Chose file...
Upload approvals
Processing

Where will the personal data be processed?
“Processing” includes any collecting, registering, storing, collating, transferring etc. of data. You must indicate all processing of personal data that will take place in the project.

- Computer belonging to the institution responsible for the project
  Computer owned/operated by the data controller. For example, processing data in a private or communal user area on the institution’s server.

- Mobile device belonging to the data controller
  Mobile device owned/operated by the data controller. A mobile device can be a laptop, camera, mobile phone etc.

- Physically isolated computer belonging to the data controller
  Not connected to other computers or to a network, neither internally nor externally.

- External service or network
  Such as providers of cloud storage, online surveys or data storage (such as TSD). Use of an external service or server requires that a data processor agreement is made between the data controller and the external party.

- Private device
  Data collection or storage on private devices such as your own computer or mobile phone etc. is not recommended and must be clarified with the institution responsible for the project.

  Data collection, storing or archiving on private devices such as your own computer, mobile phone, memory stick etc. is not recommended and must be clarified with the institution responsible for the project.

Upload guidelines/approval for processing personal data on private devices
Chose file...

Who will be processing/have access to the collected personal data?

- Project leader
- Student (student project)
- Internal co-workers  i.e. employees of the data controller
External co-workers/collaborators inside the EU/EEA
Employees of other institutions that have formalised cooperation with the data controller, or employees of other institutions that are joint data controllers.

Data processor
An external person or entity that processes personal data on behalf of the data controller, such as an online survey provider, cloud storage provider, translator or transcriber. There must be a data processor agreement or other legal agreement between the data controller and the external party.

Others with access to the personal data
Which others will have access to the collected personal data?

Will the collected personal data be made available to a third party or international organisation outside the EEA?
This includes when personal data are sent to and stored in a country outside the EEA, or when persons outside this area are given access to personal data stored within the EEA. This means that you cannot use a service provider or outsourced supplier outside the EEA, unless there is a valid basis for the transfer of personal data.

Yes
No

Give the name of the institution/organisation (if applicable)

Give the country of the institution/organisation (if applicable)

On what basis will the collected personal data be transferred? (if applicable)
Personal data can be transferred on the basis of an adequate level of protection (art. 45) or on the basis of appropriate safeguards (art. 46). Personal data can also be transferred on the basis of the exception for special situations, but only if the transfer is not repeated, concerns only a limited number of data subjects, is necessary for the purposes of compelling legitimate interests pursued by the data controller (which are not overridden by the interests or rights and freedoms of the data subject), and if the data controller has assessed all the circumstances surrounding the data transfer and has provided suitable safeguards with regard to the protection of personal data (art. 49).

Upload necessary safeguards (if applicable)
Chose file... Next
**Information Security**

Will directly identifiable personal data be stored separately from the rest of the collected data (in a scrambling key)?

It is common practice to remove directly identifiable data (name, national ID number, contact details etc.) from the collected data and give each data subject a code/number. A scrambling key is the file/list of names and codes that makes it possible to directly identify data subjects in the collected data. It should be stored separately from the rest of the collected data. In practice, this means that the scrambling key cannot be stored in the same network as the rest of the data, unless the scrambling key is encrypted.

[ ] Yes  [ ] No

Explain why directly identifiable personal data will be stored together with the rest of the collected data (if applicable)

For reasons of information security we recommend the use of a scrambling key in most projects, especially in projects where special categories of personal data (previously “sensitive” personal data) or personal data relating to criminal convictions and offences will be processed.

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Which technical and practical measures will be used to secure the personal data?

[ ] Personal data will be anonymised as soon as no longer needed

Anonymisation involves processing the data in such a way that no individual persons can be identified in the data that you’re left with, i.e. the data can no longer be linked to individual persons in any way.

Anonymisation usually involves:

* deleting directly identifiable personal data (including scrambling key/list of names)
* deleting or rewriting indirectly identifiable personal data (e.g. deleting or categorizing variables such as age, place of residence, school etc.)
* deleting or editing audio recordings, photographs and video recordings

[ ] Personal data will be transferred in encrypted form

Encryption is a mathematical method for ensuring confidentiality in that information cannot be read by unauthorized persons. For example, using an encrypted VPN tunnel or equivalent measure for external login to work-place network.

[ ] Personal data will be stored in encrypted form

Encryption is a mathematical method for ensuring confidentiality in that information cannot be read
by unauthorized persons. For example, the encryption of a hard drive to ensure the confidentiality of data when the computer is turned off.

- **Record of changes**
  Changes in the collected data are recorded/documentated with the time of the change and information about the person who made that change.

- **Multi-factor authentication**
  A method of access control where a user is granted access after presenting two or more separate pieces of evidence to prove their identity (e.g. password + code sent by text message)

- **Restricted access**
  Blocking or restricting access to the collected data for unauthorized persons

- **Access log**
  An access log shows who has accessed the collected data and when

- **Other security measures**
  For example, locking away documents, automatic screen lock after a short time for mobile devices, partitioning of hard drive, checksum/integrity check etc.

Indicate which measures (if applicable)

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**Duration of project**

**Project period** i.e. the period for processing personal data

[to] [to]

Will personal data be stored beyond the end of project period?
Personal data should not be further processed in a way that is inconsistent with the initial purpose(s) for which the data were collected. Anonymous/anonymised data may be stored indefinitely, so long as nothing else has been agreed to by the data subjects.

- **No, all collected data will be deleted**
- **No, the collected data will be stored in anonymous form**
  Stored in a form where the data can no longer be linked to individual persons in any way
- **Yes, collected personal data will be stored until**
Yes, collected personal data will be stored indefinitely.

For what purpose(s) will the collected personal data be stored? (applicable)

- Research
- Other

Where will the collected personal data be stored? (if applicable)

- At the institution responsible for the project (data controller)
- Other

Next

Additional information

Will the data subjects be identifiable (directly or indirectly) in the thesis/publications for the project? If personal data are to be published, there should be a scientific purpose for this. Data is usually published in anonymous form.

- Yes
- No

Explain why (if applicable)

Additional information

Here you can provide information that may have significance for our assessment of the project, including more detailed information about points covered in the form and information that is not covered by points in the form.

Other attachments

e.g. interview guide, questionnaire, information letter and consent form etc.
Chose file...

Next

Send for preliminary assessment