

# DESCRIPTION OF THE SCIENTIFIC RESEARCH DATA

## FILE

### Personal Data Act (523/1999) Section 10

**Date of drafting:** 28.2.2017

NB.!

The form has been modified for the purposes of scientific research and is therefore more informative than an ordinary data file description. Guidelines for filling in the form are attached. If necessary, use a separate attachment for answering.

The controller must make the data file description generally available.

<p><b>1a. Research Data file controller</b> (person / organisation carrying out research) - an organisation / a private researcher for the use of whom the data file is set up and who is entitled to determine the use of the file (in case of joint research projects, all parties and their responsibilities and duties must be explained also from the viewpoint of personal data processing)</p>	<p>Name and contact information (address, telephone...)</p> <p>PROMEQ-consortium <a href="http://www.promeq.fi">www.promeq.fi</a> Contact person of PROMEQ: Tomi Mäki-Opas, Research Director Yhteiskuntatieteiden laitos Itä-Suomen yliopisto (UEF) Yliopistonranta 1 E, Snellmania PL 1627, 70211 Kuopio telephone: 029 445 5238 / 050 323 4020 e-mail: tomi.maki-opas@uef.fi</p>
<p><b>1b. Person responsible for research or corresponding group</b></p>	<p>Janet Anand, Leader WP 5 New Start Finland! (PROMEQ), University of Eastern Finland Yliopistonranta 1 E, Snellmania building, entrance D, 3rd floor 050 596 7995 <a href="mailto:janet.anand@uef.fi">janet.anand@uef.fi</a></p>
<p><b>1c. Persons involved in the research</b> - all researchers or other persons who have a right to access the file during research</p>	<p>Janet Anand, Leader WP 5 Csilla Veszteg, Researcher Tiina Ahonen, Researcher Maija Hartikainen, Project Manager</p>
<p><b>2. Person responsible for and/or contact person on research data file issues</b></p>	<p>Name and contact information (address, telephone...) Janet Anand, Leader, WP 5 New Start Finland! (PROMEQ), University of Eastern Finland Yliopistonranta 1 E, Snellmania building, entrance D, 3rd floor 050 596 7995 <a href="mailto:janet.anand@uef.fi">janet.anand@uef.fi</a></p>
<p><b>3. Object of research / purpose of research</b> - the name of the research data file / research has to specify the purpose of the data file created during the</p>	<p><input type="checkbox"/> one-off research project, title: ----- -----</p>

research	<p><input checked="" type="checkbox"/> follow-up research, New Start Finland! will collect personal details from the participants of the survey so as to be reach the participants for a follow up-survey, inclusion in a comparative group and to prevent duplication of participants in project interventions and for some limited profile analysis.</p> <p>duration: Research project: 2016-2019 Person register: 2017-2018</p>
----------	--

OFFICE OF THE DATA PROTECTION OMBUDSMAN

MODEL FORM

23 Aug 2004

Tel: +358 10 36 66700

Tel: +358 10 36 16670 (information service 9 a.m. to 3 p.m.) Fax: +358 10 36 66735 [www.tietosuoja.fi](http://www.tietosuoja.fi)

**[Unofficial translation]**

<p><b>4. Contents of the data file</b></p> <ul style="list-style-type: none"> <li>- distinguishing data (such as name, personal identity code, date of birth)</li> <li>- research information</li> </ul>	<p>Following personal information is gathered from the participants of the study: -name -year of birth -address -e-mail address -telephone number (signature, date, place?)</p>
<p><b>5. Composition of research data</b></p> <ul style="list-style-type: none"> <li>- from whom, what data and on what grounds</li> </ul>	<p>Personal information (name, year of birth, address, e-mail address and telephone number) is collected from the participants of the survey by a consent form. Before filling out the survey, participants fill out their personal details and sign a consent form as an approval to take part in the survey and allow researchers to contact them for the follow-up-survey.</p>
<p><b>6. Research is carried out</b></p>	<p><input checked="" type="checkbox"/> nationally <input type="checkbox"/> within EU/EEA territory <input type="checkbox"/> outside EU/EEA territory</p>
<p><b>7. The principles of data file protection</b></p> <ul style="list-style-type: none"> <li>- the method of protection during different phases of processing</li> <li>- the data file collected during research includes both manual and</li> </ul>	<p><input checked="" type="checkbox"/> data is confidential</p> <p>Manual data: Researchers will collect the consent forms (which will include the personal details of the participants of the study) and surveys in hard copy and will store the forms at the University of Eastern Finland, in a locked cabin. Personal details are kept separate from the research data for security reasons.</p> <p>Information recorded in digital data systems:</p>

<p><b>digitally stored data (logical data file)</b></p>	<p>Personal details will be inserted onto an excel sheet. Each participant will be given an identifying code and number which will also be recorded on the sheet and excel document will be stored in Teamplace, a site that requires research team user account and password to gain access to file. Files will be destroyed after the completion of the analysis of the second survey.</p> <p><input checked="" type="checkbox"/> user account</p> <p><input checked="" type="checkbox"/> password</p> <p><input type="checkbox"/> registration of use</p> <p><input type="checkbox"/> access control</p> <p><input checked="" type="checkbox"/> Distinguishing data will be removed after the analysis phase</p> <p><input type="checkbox"/> Data are analysed by means of distinguishing data because (state the grounds for storing distinguishing data):</p>
<p><b>8. Research data file; destroying or transferring to archive</b></p>	<p><input checked="" type="checkbox"/> The research data file will be destroyed Personal details of the participants (paper forms and electronic excel file) will be destroyed after the follow-up-survey round and analysis is completed.</p> <p><input type="checkbox"/> The research data file will be transferred to an archive</p> <p style="padding-left: 40px;"><input type="checkbox"/> without distinguishing data</p> <p style="padding-left: 40px;"><input type="checkbox"/> with distinguishing data</p> <p style="padding-left: 40px;">Location:</p>

## Guidelines for filling in the DESCRIPTION OF THE RESEARCH DATA FILE

(The numbers refer to the corresponding items on the form)

1. a) The controller carrying out research refers to an *organisation, individual researcher or a research group* for the use of whom a data file is set up and who is/are entitled to determine the use of the file. In other words, the body or person carrying out the research is responsible for the research data obtained during the research project. Please note that a researcher who, because of an employment relationship, is in charge of a research project carried out in a research institute or a hospital is not considered a controller. In such cases the controller is the research institute or the hospital in question. An independent researcher carrying out his or her own private research is, however, considered a controller.

If the study is conducted as a joint research project between several research institutes or hospitals, the responsibilities and duties of different parties must be defined from the viewpoint of the processing of personal data.

If the controller *is not established in the territory of the European Union*, but uses equipment located in Finland in the processing of personal data, except when the equipment is used solely for the transfer of data through the territory, the controller must *designate a representative established in Finland*. In addition to the controller, the *representative, including appropriate contact information, is entered in this column*.

b) The person responsible for research is entered in this column. This refers to persons who are in charge of the research project in question and have been appointed by the body or person carrying out the research or the controller. This does not, for example, refer to a person who is in charge of general research administration. Instead of a responsible manager, a group responsible for research can be entered here.

c) All researchers and other persons who process personal data in the research data file during the research project are entered here.

2. The person in charge of data file issues is a person who is able to provide detailed information to the data subject and to whom data subjects may submit requests concerning rectification of erroneous information or access for the purpose of exercising inspection rights.
3. The purpose for which personal data is being processed in the research project is entered here in a specified and brief form. In case of scientific research, the requirement for specificity means that 'research' must refer to a research project limited in its scope and duration. Please note that general definitions such as 'cancer research' do not meet this requirement. The controller must give a name for the file established during research, which distinguishes it from other research data files managed by the controller.
4. The *contents* of the file must be defined *before* the research data file is *set up*. The content types of the data recorded in the personal data file are entered in the description, in other words, what data on individuals are recorded in the file. The information must be so explicit that the reader understands what data have been recorded in the file. Distinguishing data such as name, date of birth (personal identity code) and address should be given separately from each other. In addition, information on what kind of research data/treatment data are collected in the data file must also be provided. Please note that only personal data *necessary* from the viewpoint of the purpose of processing may be collected. If necessary, *a separate appendix* can be used to list the content of the data.  
If the file contains several data file sections, organise the data under subheadings.
5. The composition of a research data file is entered here (from whom, what information and on what grounds/the consent of the data subject, the provision of the act indicated). This section also describes the content of the data file.
6. If necessary, information on whether the research is carried out nationally, within EU/EEA territory or outside EU/EEA territory is entered here.

7. The principles of data file protection for manual and digitally stored data are entered here. If the personal data recorded in the file are subject to confidentiality provisions (provisions pertaining to secrecy obligation and/or confidentiality of a document), the relevant entry is made here. It is important that the principles of data protection are explained in order to assess whether the protection obligations as provided in Sections 5 and 32 of the Personal Data Act have been complied with. If the data will be analysed by means of distinguishing data, the grounds for storing distinguishing data at this stage are indicated here.
  
  8. This column contains information on whether the research data file will be destroyed after the completion of research or whether the file will be archived. If the data file will be archived, the location where it will be archived and whether it will be archived with or without distinguishing data are entered here.
-