

Disability Studies in Nederland: Code of Practice for Researchers

2016-2017

This Code should be read and followed by all researchers working for or with Disability Studies in Nederland.

Researchers may also need to regard other Codes of Practice, for example those issued by a university or organisation with which they are also affiliated, or by professional organisations that they are members of.

1. Principles and Application

- 1) DSiN expects all research carried out under its auspices, or by its employees or contractors, to adhere to the highest ethical standards.
- 2) This Code of Practice applies to all DSiN employees, contractors, and external research collaborators working on projects affiliated with DSiN.
- 3) This Code will be reviewed annually.

2. Accountability

- 1) For all research projects, the project leader / principal researcher is accountable for ensuring that all researchers and external research collaborators are aware of the Code of Practice and adhere to its standards and guidelines.
- 2) There are multiple areas of accountability that each researcher must have regard for. These are:
 - a. The ethical basis of the research and research design
 - b. Safety of all involved in research
 - c. Sound financial management of research, including accountability to DSiN and to any additional public or private funders
 - d. Sound research project management, including delivering scheduled outcomes in a timely fashion
 - e. Management, use and security of research data in a way that meets the requirements of relevant Dutch and EU laws concerning the management of personal information
 - f. Ensuring that research results are disseminated in a timely way, and that accessible summaries are made available to research participants and disabled people and others who may benefit from the research
 - g. Maintaining adequate research records and providing these to DSiN as required
 - h. Ensuring that research participants give their consent without coercion or pressure, are informed of any risks, and are aware of the broad purpose of the research project and its funders
 - i. Taking account of and minimising risks to research participants and researchers
 - j. Considering how research derives from and affects the work of others, and respecting the rights and reputation of others
- 3) When peer reviewing research proposals or results (including manuscripts submitted for publication), researchers must protect the confidentiality of information

provided, disclose any conflicts of interest and any areas of limited competence, and must not misuse or misappropriate the content of the material being reviewed.

- 4) Researchers must be honest and lawful in respect of their actions relating to research and in response to the actions of other research workers. This applies to the whole range of research activity, outputs and deliverables, including applying for funding, generating and analysing data, publishing results, choice of research methods and acknowledging the direct and indirect contribution of colleagues, collaborators and others.

3. Research data

- 1) Research workers must keep clear and accurate records of the research procedures they followed and the results obtained, including interim results.
- 2) Research data must be recorded in a durable and auditable form, with appropriate references so that it can readily be recovered. Unless directed to do otherwise, data about individuals should always guard anonymity.
- 3) Data should be stored in a secured form. If it is on a personal computer, the computer should be protected by a password. If it is stored on removable media, such as an external hard drive, USB stick, or CD, the removable media should be kept secure.

4. Authorship

- 1) All publications should acknowledge the contributions of everyone who has conceived, executed or interpreted at least part of the research reflected in the publication.
- 2) Usually, this will mean being listed as a co-author of the research. Being listed as a co-author requires consenting to the content of the publication.
- 3) If a contribution was too minor to warrant being listed as a co-author, it should nonetheless be acknowledged in the publication or in a list of acknowledgements. Funders, organisations, archives, and research sites should also always be included in acknowledgements, unless this would compromise confidentiality of research participants.

5. Ethical review

- 1) All DSiN research projects must adhere to the Ethical Review procedure outlined in this section.
- 2) First, the project leader / principal researcher should conduct an Ethical Review self-assessment using the form provided (see DSiN Ethical Review Self-Assessment Form)
- 3) This form must be placed on file with DSiN.
- 4) If this form indicates that further review is needed, the research project plan and associated documents must be sent to the DSiN Ethical Review Committee for approval.
- 5) The result of this process must be placed on file with DSiN.
- 6) DSiN will form an Ethical Review Committee, made up of two DSiN staff plus a third non-DSiN academic who will be consulted if the internal committee cannot agree or feels that additional insight is required.
- 7) If the Ethical Review Committee requests changes in the research design, permissions forms or procedures, or other aspects of the research, these must be

followed by the researcher(s).

6. Additional requirements

- 1) Project leaders / principal researchers must ensure that they are familiar with any additional rules and requirements of research funders or partners, and that these are followed.
- 2) Should a researcher become aware of any situation that could negatively impact the reputation of DSiN, any form of misuse or loss of finances or equipment, or any potential or actual harm to research participants (including harm that is not connected to the research project), this must be reported to DSiN immediately.

7. Research misconduct

- 1) Not complying with this Code of Practice will be defined as research misconduct, as will the following actions:
 - a. Fabrication of data or permissions
 - b. Falsification of data or deceptive manipulation of research results
 - c. Plagiarism in any form
 - d. Misrepresentation of the origin of ideas, data, or authorship
 - e. Failure to declare financial or other material interests by researchers or funders
 - f. Breach of any duty of care to co-researchers or research participants, including, but not limited to, placing others at risk of harm, and unauthorized disclosure of personal information or the identity of individuals
 - g. Failing to obtain informed consent from research participants
 - h. Unauthorised use of information obtained confidentially
 - i. Failure to disclose an actual or potential conflict of interest that could bring DSiN or a research partner into disrepute or compromise research integrity
 - j. Inciting others to commit research misconduct
 - k. Failure to declare, when known, that a research partner or collaborator has committed research misconduct or is under investigation for misconduct
 - l. Fraud, including research fraud and financial fraud
- 2) Because an accusation of research misconduct is a serious matter (and if false, could be considered defamation), any allegations of research misconduct should be made confidentially and directly to the current Director of DSiN only. The Director will be responsible for investigating the allegation and determining what measures should be taken if research misconduct is found to have occurred.

8. Intellectual property

- 1) When working on any project managed, carried out or funded by DSiN, researchers need to discuss the issue of intellectual property with DSiN and come to an agreement before proceeding.
- 2) It is our intention that unless otherwise prohibited (for example by a separate agreement with a funding agency or institution), findings and/or (versions of) final outputs from all research in which DSiN is involved will be available via an open source archive managed by DSiN. Working links to an external open source archive are also acceptable.

Form A: DSiN Ethical Review Self-Assessment Form

Name and email address of project leader / principal researcher¹

Names and contact details of any co-researchers

Title of research project or grant:

Funding body:

Please circle the appropriate answer for each question that follows:

Does your research involve working directly with, interviewing or observing people?

YES NO

Are the research process or results likely to expose any person to physical or psychological harm?

YES NO

Will you have access to personal information that allows you to identify individuals, or to company confidential information (that is not covered by a separate confidentiality agreement)?

YES NO

Are there any other ethical issues that you think warrants further ethical review?

YES NO

If the answer to all of the above questions is NO, you do not need further ethical review to begin work. Please send a completed copy of this form to DSiN, and retain a copy for your research files.

If the answer to any of the above questions is YES, please proceed to **Form B: DSiN Ethical Review Form**

¹ All research projects must have a named Principal Researcher or Project Leader.

Form B: DSiN Ethical Review Form

Please add additional pages if you need more space to explain any issue or process.

If your research will involve working directly with, interviewing or observing people:

- Please include a copy of the permission form you intend to use when submitting this form (see **Sample DSiN permissions forms** for examples).
- Please complete the form below.

DSiN's policy is that we *presume competence*: We believe that in most cases, adults with disabilities (including most adults with intellectual, developmental and mental health conditions) can make good decisions about whether or not they wish to take part in research – but only when they have been given adequate information in a format they can understand, and when we ensure that no pressure or coercion is involved in gaining consent. Please explain below what issues may exist in regards to informed consent, and what steps you will take to ensure informed consent is obtained in an ethical manner:

If you will be working with people with disabilities who are under the age of 18, or who have been found legally unable to give consent, or who you have good reason to believe are unable to give consent, even if information is presented in an accessible format, please explain who will be asked to give permission on these individuals' behalf. Additionally, explain how you will ensure that a) people with disabilities themselves have adequate information about the research process and its purpose and b) that no pressure or coercion is involved in obtaining consent.

Minimising potential harm

If your research could expose any person (researcher, research participant or others) to physical or psychological harm, please explain below what steps you will take to minimise these risks.

Safeguarding personal and other confidential information

Please explain what steps you will take to secure personal information about research respondents, and to secure any other confidential information you may have access to.

Please explain what steps you will take to anonymise research respondents in any research outputs or processes.

Additional issues

If you believe there are any other issues that may require ethical consideration, please detail these here, and explain what steps you will take to address them.

Sample DSiN permission forms and guidance

You will find two sample permission forms attached to this guidance document. These models can be adapted to fit your project, or you may want to write your own. In any case, please consider the following principles when creating and using permission forms.

The purpose of permission forms

Permission forms are not about “ticking boxes” or convincing people to agree: they are an essential research tool.

They should inform potential research participants about the broad purpose of the research project, who is funding it, and any risks involved.

Language used should never have the effect of applying pressure or coercing participation.

All permission forms need to include a section explaining that permission can be withdrawn at a later date, and explain how a research participant can do so.

All permission forms should explain how confidentiality will be protected.

Accessibility

Think about the language level used. Make sure that your research respondents can read and understand the form.

If your research respondents have difficulty with reading for any reason, think about alternative ways to present the information on the form to them. These might include:

- Reading the form out loud.
- Making a recording or video recording of the text on the form.
- Presenting the information in a visual format, or in a format that includes both text and visuals.

Consent can be recorded or videotaped, or conveyed using a textual or visual format other than handwriting, when this is necessary because of an impairment.

Understanding

How the form is presented and by whom also makes a difference. Always try to take time to discuss the research and the form with each participant, answering any questions they may have as completely as possible.

This is especially important in research projects where you are working with children or with adults who are unable to give their own consent. While a parent or guardian may give consent, it is the researcher’s job to ensure that the *participant* understands why they are taking part and what will happen.

It is a core principle in Disability Studies that people with impairments should benefit from research that involves them. This benefit can be tangible (improving a service they receive, improving self-advocacy skills) or somewhat intangible (feeling proud about their contribution, improving general understanding of a condition or service). Barton (1999)

suggested that inclusive or emancipatory research on disability must engage with three key questions:

- Who is this work for?
- What right do we have to undertake it?
- What responsibilities come with it?

In no case should participants be exploited to meet the researcher's aims and then forgotten. This leaves people feeling let down, and reduces the benefit to them from taking part. For this reason, researchers should always think about how research results will be communicated to participants, and also how they will be shared with others who share the participants' impairment or use similar services.

Nind (2008) has written an excellent research review that covers many tricky aspects of research design, consent, and voice when working with disabled people. It includes excellent suggestions for ways of making consent forms and other research processes accessible and ethical. Researchers are strongly encouraged to read it, follow its references to explore pertinent issues in depth, and consider ways to improve their overall research design as well as consent/permissions procedures.

RESOURCES

Barton, Len (1999) "Developing an emancipatory research agenda: Possibilities and dilemmas," in: P. Clough and L. Barton (eds.) *Articulating with Difficulty: Research Voices in Inclusive Education*. London: Sage, pp. 29-39.

Nind, Melanie (2008) *Conducting Qualitative Research with People With Learning, Communication and Other Disabilities: Methodological Challenges*. Southampton: National Centre for Research Methods. Online at:
<http://eprints.ncrm.ac.uk/491/1/MethodsReviewPaperNCRM-012.pdf>

Dear respondent:

We are carrying out research into [x]. The goal of this research is [x].

We would like to request that you contribute by being interviewed in person, or using email or Skype.

We are also hoping that some research participants will be interested in being a co-researcher by [x: for example, interviewing other people or contributing to data analysis]. We will provide you with training and support to do this. Co-researchers have the option of being listed by name in any publications. We can also provide a letter of reference to co-researchers, which could be helpful with future university or work applications.

Our research results will be used as the basis of an article to be published in an academic journal. We may also present the results at a conference. We would be happy to provide you with a copy of any research publications.

You will not be quoted by name in any article or presentation—all respondents will be identified using pseudonyms. We will not provide any descriptive details about you that would make it easy for someone to guess who you are. We keep our research notes on password-protected computers or locked files.

You have the right to withdraw from the research project at any point prior to [date].

It is important to us that you feel comfortable with how the information is collected, and with how it will be used. For that reason, we ask that you sign below (typing your name in the space provided if returning the questionnaire electronically) if you agree to take part.

Sincerely,

[researcher name]

I agree to participate in this research.

Sign or type your name above

Tick the following boxes as appropriate:

- I agree to participate in this research by being interviewed.
- I would like to be a co-researcher on this project.