

# A Practical Framework for Ethics – the PD-Net Approach to Supporting Ethics Compliance in Public Display Studies

Marc Langheinrich

University of Lugano  
Via G. Buffi 13  
Lugano, Switzerland  
+41 (59) 666-4304

[langheinrich@acm.org](mailto:langheinrich@acm.org)

Albrecht Schmidt

University of Stuttgart  
Pfaffenwaldring 5a  
Stuttgart, Germany  
+49 (711) 685-60048

[albrecht.schmidt@acm.org](mailto:albrecht.schmidt@acm.org)

Nigel Davies

Lancaster University  
Comp. Dept., InfoLab 21  
Lancaster, England  
+44 (1524) 510327

[nigel@comp.lancs.ac.uk](mailto:nigel@comp.lancs.ac.uk)

Rui José

Universidade do Minho  
Campus de Azurem,  
Guimaraes, Portugal  
+351 (253) 510-307

[ruj@dsi.uminho.pt](mailto:ruj@dsi.uminho.pt)

## ABSTRACT

Research involving public displays often faces the need to study the effects of a deployment in the wild. While many organizations have institutionalized processes for ensuring ethical compliance of such human subject experiments, these may fail to stimulate sufficient awareness for ethical issues among all project members. Some organizations even require such assessments only for medical research, leaving computer scientists without any incentive to consider and reflect on their study design and data collection practices. Faced with similar problems in the context of the EU-funded PD-Net project, we have implemented a step-by-step ethics process that aims at providing structured yet light-weight guidance to all project members, both stimulating the design of ethical user studies, as well as providing continuous documentation. This paper describes our process and reports on 3 years of experience using it. All materials are publicly available and we hope that other projects in the area of public displays, and beyond, will adopt them to suit their particular needs.

## Categories and Subject Descriptors

K.4.1 [Computers and Society]: Public Policy Issues—Ethics, Privacy; H5.2 [Information Interfaces and Presentation]: User Interfaces—Evaluation/methodology; K6.1 [Management of Computing and Information Systems]: Project and People Management—Management techniques; K7.4 [The Computing Profession]: Professional Ethics—Codes of good practice;

## General Terms

Documentation; Experimentation; Legal Aspects; Management

## Keywords

Data protection; Ethical awareness; Human subject experiments; In-the-wild studies; Public displays

## 1. INTRODUCTION

Research in many aspects of mobile and ubiquitous computing is increasingly multi-disciplinary, multi-site and involves ethnographic observations and numerous user studies. Pervasive display research is perhaps the canonical example: project teams often consist of computer scientists, designers, architects and social scientists and experiments tend to include both lab-based studies and extensive field work [1]. Of course, these

characteristics don't just relate to pervasive display research – many areas such as usable security, smart homes, behavior change applications and citizen science share common traits.

One of the significant challenges in conducting this type of research is in gaining appropriate ethical approval. For some, ethics is at the very heart of their discipline [2][3] – for others it has become an administrative hoop that one has jump through [4]. The situation also varies significantly by country: in the US and the UK for example there are well established ethics procedures for human subject research and institutional review boards (IRBs) providing a well-defined process and oversight. These procedures typically require researchers to submit detailed descriptions of planned studies before permission to conduct the experiment is granted. However, not all institutions have such procedures – especially in many parts of Europe where gaining ethical approval is often not required unless the research is in the medical domain.

A formal ethics process involving IRB review also suffers from a shortcoming in that it is typically only conducted once at the start of the project. This raises two significant challenges. Firstly, in computer science driven projects the focus often changes during the course of the research due to the availability of new technologies. More critically, the IRB process often involves just the PIs of projects as the students and researchers are not in place at the outset. Finally, we note that it is also the case that ethical approval is just one consideration in experimental design. In particular, additional approval may be required for data storage and data retention in order to comply with data protection legislation and privacy regulations.

As part of the PD-Net pervasive display project [5] the authors, all PIs at their respective institutions, have had to face these problems of experimental design and ethical compliance. We have created a project-wide ethical approval process in order to better address ethics issues throughout the project lifetime. This process does not replace existing local ethics procedures – rather it looks to introduce a framework that supplements these in the context of the project and involves all project participants. The approach described in this paper has been successfully applied and extended by different researchers over the last three years. In addition to the ethical dimension, the process introduced has (subjectively) strengthened the reflection of researchers on the research questions before and during the design and execution of studies.

This paper describes the design principles, the process, and our experiences of creating and using this framework. We hope that the framework is useful to others pursuing research in the area of pervasive displays and, more generally, in the areas of mobile and ubiquitous computing. The detailed process description and the related documentation are published and available to other researchers (cf. section 6).

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## 2. DESIGN PRINCIPLES

Given the danger that one simply “goes through the motions” if ethics is seen as merely an administrative hurdle on one’s way to an exciting study, we wanted to make sure that its use within the project involved only minimal overhead yet both helped create awareness and ensured the proper treatment of subjects and their personal information. As public display research often employs a wide range of evaluation methods [6], the ethics process should support existing methods and be extensible for new ones.

Our process was thus modeled around the following requirements:

- *Low barrier to entry*: team members without any prior exposure to the topic should be able to quickly learn the basic motivation behind the process and its significance in human subject research. We wanted team members to be able to start implementing the process right away, without reading a textbook; yet arrive at a thorough understanding of the issues.
- *Easy to apply, scalable in use*: to keep the overhead low, simple studies should be simple to process, while complex ones may require more effort. Team members should only need to look at those parts of the process that are relevant to their particular setting.
- *Adaptable to different legal and institutional requirements*: as project members were from different institutions in different countries, the respective backgrounds should be able to fit into the process.
- *Adaptable to different types of studies and practices*: the same process should work for a range of study types, including psychological experiments, in-the-wild studies, focus groups, and walk-up interviews.
- *Process reuse*: given the large number of envisioned studies, the process should not become repetitive – repeating a certain type of study should involve only minimal efforts, while a new study design should require more active considerations. Team members should be able to build on previously conducted studies and their respective documentation to speed up subsequent studies, also across sites.
- *Value beyond ethics*: the process should support secondary purposes, such as documentation or offering practical advice for dealing with human subject studies and collected data. Team members should be prompted to reflect on their study beyond ethical questions in order to help sharpen the overall research question

To address these requirements we created a process that consists of the following components:

1. An independent *ethical advisory board* (EAB) to provide external input to the project.
2. *Base documentation* describing the process and the basic background and motivation.
3. A set of *study process templates* (SPT) that are created “on-demand”, i.e., whenever a new type of study is planned, and then sent to EAB members for comment.
4. Ethical *worksheets* that are filled in for every study, citing the governing process template and describing the study, its ethical implications, and the concrete measures taken to mitigate them in detail.

The next section will describe our process in detail. We are making the process materials available to the community – see section 6 for more information.

## 3. PROCESS

From the ethical workflow point of view, the project is divided into 3 phases: the preparatory phase, the research phase, and the closing phase (cf. Figure 1).

1. During the *preparatory phase*, the project partners jointly form an “Ethics Advisory Board” (EAB). Advisory board members (typically one per partner) are ethics experts from each of the partners, e.g., members of the organization’s legal team or institutional review board, or the data protection officer. EAB members are asked to review a small number of process documents (see below) over the course of the project.
2. During the *research phase*, project members follow the ethics process described below for each human subject study that is planned. Initially, novel studies will require feedback from the EAB, but as the project progresses, EAB input will be less and less frequent.
3. In the *closing phase* of the project, i.e., after the project funding ends, data deletion commitments must be enforced and a final data processing report submitted to the EAB.



Figure 1: Three Phases of the Ethics Process

### 3.1 Preparatory Phase

During the preparatory phase, the project PIs prepare the background documentation, i.e., the process description (see section 3.2), an introductory document (“ethics primer”), as well as any study process templates/SPTs (see below) that they can readily identify as being applicable to the human subject studies foreseen in project. The initial documentation is helpful to recruit EAB members prior to the project start, and should thus be the very first step.

The role of the EAB is to provide external ethical oversight. In places with an existing institutional review board (IRB), this looks like a redundant structure. However, in our experience, IRBs at many European Universities only focus on medical/psychological research, if they exist at all. Institutions with an IRB should thus recruit an EAB member from their existing IRB, while organizations without an IRB should seek a local expert in ethical issues, e.g., from the legal team, a legal/philosophical/theological faculty, or the data protection office (a mandatory post in many European organizations). Recruitment should point out the relatively low number of exchanges needed during the research phase – we found that no more than half a dozen explicit interactions were needed. Sample invitation letters are available on our Website (see section 6). Note that no direct coordination among EAB members is needed (though this is possible and adds value to the members) – instead, each EAB member independently provides feedback to the planned studies.

The documentation that we used in the context of our own project are available as “seed documents” (section 6) and should be easily appropriated by other projects by filling in the appropriate data. Sample pages are also shown in the appendix.

The preparatory phase concludes with the start of the project.

### 3.2 Research Phase

The research phase will see repeated application of the core study approval process, as described below. At the heart of this process are the so-called Study Process Templates (SPT). These templates describe a particular type of study (e.g., lab experiment, field observation), or a particular procedural or technical challenge (e.g., secure storage, informed consent). Each concrete study is mapped onto one or more of those templates, allowing researchers to quickly identify the challenges of a particular study type, as well as using the template to follow proper procedures. Ethical feedback from EAB members is *per template*, rather than per study. This not only lowers effort on behalf of the EAB members, but also streamlines procedural overhead of the entire process.

The full set of steps described below (i.e., 1-5) is thus only performed for novel studies for which no SPT exists yet. Once a particular study has been performed, subsequent similar studies across all member sites only require the very first step, i.e., filling out a detailed worksheet describing the actual instance of a study type. Similarly, the process is easily extendable and allows for cross-project reuse. The worksheets double as project documentation, process guidance, and as an educational tool.

Figure 2 shows the core elements of the process, and how they interact during the preparation of a study. The five steps are:

1. Fill out Ethical Worksheet prior to planned study
  - a. Prepare Consent Form if needed (see “Consent” SPT)
2. If needed, seek local approval from local Institutional Review Board (IRB) and regulatory bodies
  - a. If IRB assessment required, prepare necessary documents and submit
  - b. If regulatory approval required, prepare necessary documents and submit
  - c. Incorporate any feedback, resubmit if necessary
3. Identify type of research and consult set of appropriate Study Process Templates (SPT)
  - a. If no SPT matches, create new SPT for this class of research and submit to project Ethical Advisory Board (EAB) prior to planned beginning of study
    - i. Incorporate any feedback from EAB, resubmit to EAB if necessary
    - ii. Complete Ethical Worksheet with results from EAB, IRB, regulatory assessments
4. If new IRB approval and/or EAB assessment, submit results to project Coordinator prior to planned begin of study
5. Proceed with the planned study only if all relevant SPTs have been approved by the EAB and all local IRB issues (if applicable) have been addressed.



Figure 2: Study Approval and Feedback Process

The use of process templates ensures not only uniformity across all project partners and studies, but also that review board members will be able to give detailed and meaningful feedback, as this greatly reduces the number of requests made to the board. Note that EAB members need to have access to all worksheets and templates at any time.

All existing documentation is publicly available (cf. section 6). So far, we have created the following documents and templates:

- *Background “Legal Analysis”*: This summarizes the legal situation with respect to data protection in each of the partners’ countries. We envision this document to be extended in a Wiki-style manner, allowing other researchers to add information for other countries as needed. It also holds contact information of legal representatives/IRB members at each site.
- *Background “Ethics Primer”*: This document summarizes the core ethical principles, its history and motivation, as well as the overall process. It is intended as a primer for all new project members, as well as serving as a process handbook.
- *Template “Secure Storage”*: This practical guide summarizes our experiences with implementing secure storage and processing of sensitive project data (i.e., personal information). It contains information about encryption tools (e.g., TrueCrypt, EncFS) as well as general data security procedures (e.g., pseudonymization, secure deletion).
- *Template “Informed Consent”*: This practical guide describes the background of requiring informed consent from study subjects and outlines the proper procedures for obtaining it in different circumstances (e.g., lab experiment vs walk-up interviews). It is in turn referenced in most of our study process templates as the basis for human subject studies.
- *Template “Interviews & Surveys”*: This process template describes the procedures we used to perform any type of interview or survey. It discusses data collection strategies (e.g., recording vs notes), data storage, and questionnaire design (from ethical/data protection point of view).
- *Template “Public Trials”*: This process template describes our approach to in-the-wild studies, where obtaining individual consent from passers-by is often not possible. It sets out limits on what kind of data should be recorded (e.g., using cameras) and how such A/V recordings will need to be performed if needed. It also points out how note taking can often be an adequate substitute for blanket video recordings.
- *Template “Volunteer Studies”*: This applies to lab experiments that recruit healthy adult volunteers, focusing on study interruption, participant stress, and recording issues.
- *Form “Ethical Worksheet”*: The Ethical Worksheet is the main entry point into each planned study. It requires the detailed documentation and rationalization of the study, and explicitly links to one or more study process templates. If no adequate SPT exists, it prompts the creation of a new process document that will need subsequent feedback from the EAB.
- *Form “Informed Consent”*: Project partners share a collection of informed consent forms that can be easily adapted to various study designs.

At the outset of the project, all documents are provided to EAB members for comment. As new SPTs are created during the project lifetime, only these will need to be reviewed by the EAB, which significantly lowers the overhead for EAB members without hindering their involvement in the process.

The use of SPTs makes the process both lightweight and flexible: project-specific changes can be made at any time in the process, e.g., further studies, new types of devices, new mechanisms for

data collection, or new analysis methods. At the same time, the process is open and extendable: worksheets and forms can be added and modified, in order to fit the needs of a particular project or project partner (e.g., made more detailed in order to fit an institutional or national requirements).

### 3.3 Closing Phase

Each ethical worksheet contains a final section detailing the collected data's lifetime. By default, collected personal data must be deleted within 3 months after the end of the project, though the worksheet also allowed for shorter periods of storage. By explicitly linking data storage to security efforts, the process helps illustrate the cost of keeping unneeded personal information around, and encourages a frugal use of such data. For data to be stored beyond the project's lifetime, researchers would need to detail the exact anonymization procedure in place for removing personally identifiable information. Finally, a summative report on the studies undertaken, the data deleted and anonymized, and the process templates developed, will be submitted to the EAB after the end of the project.

## 4. CASE STUDY

Within the PD-Net project we applied the process described for all our experiments involving human subjects. The responsibility for following the process, preparing the documents (and if required extending the framework) ultimately resided with the principal investigator for each institution. In practice, individual researchers and research students participated in the process and benefitted from this engagement. Prior to conducting any studies, project members were required to read the ethics primer (we found this took approximately 30 minutes), and were encouraged to discuss the document with their fellow researchers.

One of the first examples where the process was used was a set of observational studies and interviews with the skater community in Lugano to understand how they might appropriate a situated public display. The study title was "Uncovering Lugano Skater Community Values and Practices". The worksheet included a 50 word description of the study: *"The main goal of this study is to uncover current values, beliefs, and practices of the skater community in Lugano. This also entails mapping macro- and micro-communities, as well as their interconnections within and without their community hub. This information should be solicited through online surveys, observations, and in-depth interviews."* Additionally the goals for the study were described: *"The outcome of this study should be a qualitative description of the values and beliefs shared within Lugano skater community. The study will also look into how technologies are used by community members to express those values and beliefs, as well as how they are used for communication and coordination."* These summaries not only served to frame the ethical discussion, but also helped researchers to better frame and articulate their planned study.

The worksheet also asked for a list of research methods the researchers planned to use. In the case of the skater study, the researchers stated: *"Online as well as offline surveys, Walk-up interviews, In-depth interviews, and Observations"*. Each of these methods was then explicitly linked to an existing process template (cf. section 3.2). In case a particular method had been identified for which no process template yet existed, a new template would have needed to be created and discussed with the EAB members. Finally, all the researchers involved in the study were named, the appropriateness of the methods was argued the data to be collected and the approach to data storage and data retention was specified. The worksheet also contained a brief discussion of risks: *"Participants could be identified in the observational*

*pictures. Participant's motives for joining the community could be traced back to them as in-depth interviews will be recording voice."* and the precautions taken: *"No names are recorded electronically – we use only random identifiers [...] Pictures and voice recordings will be stored in encrypted files [...] with limited access."* The "Guide to secure storage" process template was referenced in order to understand the best way to implement the outlined precautions. As described in section 3.3, data deletion was explicitly planned.

We found that completing the forms took a relatively short period of time and that this "overhead" resulted in researchers being better prepared for the experiment. By actively engaging with a project-wide ethics process team members took ownership of the issues in doing ethical research.

## 5. DISCUSSION

In this section we provide a short discussion on our experiences of applying the process in the context of the PD-Net project for experiments by both staff and students. Overall we gained experience with this process in over two dozen different studies.

### 5.1 Ethics process buy-in

Following a defined process that ensures ethical conduct is widely accepted in the research community and considered good practice. No researcher would question the necessity of such an approach and there is general agreement that it is essential in research to prevent unethical studies from being conducted. When preparing a study or running an experiment the additional (administrative) overhead of a formal ethics approval process is often seen as a burden by the individual researchers. However, it is important to note that the absence of an approval process or where the procedure is not required by local legislation can also be a burden for the researchers as they carry the full responsibility for a trial without receiving feedback. Hence, we found that researchers perceived value in the process even when they were not required by their own institution to gain ethics approval. We strongly argue that an ethics process should be in place for user research as there is a clear value for society as well as for the individual researcher.

### 5.2 International applicability

The requirements for conducting human subject studies, observing users, or experimenting with interactive artifacts differ significantly between countries. We experienced these differences first hand in PD-Net, which drove the design and improvements of the approach described in this paper. The process was deliberately designed to have a modular educational element that only requires researchers to learn what is required in the context of the studies to be conducted. In addition, by adopting a modular approach we were able to ensure that the ethics process complied with the four national requirements the project partners were operating under, without duplication of effort. If a particular national law or university rule would require a certain step or specific procedures, the a process step in our approach could easily be replaced or adapted, without creating additional effort.

### 5.3 Value of modularity and openness

Once the core of the process was defined and the documents created, it become fairly easy to extend the approach to new study types. Our experience showed that researchers could easily extend the process to a new type of study after having used one of the existing templates. The ethics primer was designed as being universal and we did not encounter any cases where it was not applicable – though we note that our work has been mostly conducted within a fairly limited domain.

For the creation of a new template researchers usually took an existing template as example and created a new one based on this. The effort for this was less than a few days and typically led to an in-depth reflection of the new question or study type. While creating the template was triggered by the requirement of the ethics process, the reflection had a positive effect on the study design and even more generally on the empirical approach taken.

In a second step the worksheet was reviewed to determine if questions were missing or not applicable. By having the means to extend the process, all project members became more involved in the approach, reflected better on experiments and observations, and gained ownership of the process, ultimately also providing materials for other to use in similar studies.

#### 5.4 Value of a detailed worksheet

Before conducting any observation, study, or experiment, an ethics worksheet had to be completed. Initially this was seen as an extra burden as it typically required 1-3 hours to answer the questions in the worksheet. Over the course of the project, as the researchers became more accustomed to the process, they appreciated this step. The comprehensive formulation of the experiment or study, the clear articulation of the research question, and the reflection on participant selection and potential outcome turned out to be a useful resource in the paper writing process after the study was completed. Team members acknowledged that by being forced to be very specific about the research questions involved they re-thought the experiment and sharpened their research questions.

#### 5.5 Limitations

The process we describe and implemented in PD-Net does not attempt to capture or discuss the societal implications of the research. While this is an important aspect of any scientific endeavor [7][8] we have focused our efforts on ensuring the ethical treatment of study subjects and their personal data [9].

### 6. RESOURCES

All of our supporting material is publicly available via the project Website at <http://pd-net.org/ethics/>. We envision the Website to become not only a point for downloading and reusing the material described above, but also to open up an exchange of templates, experiences, and process improvements.

### 7. CONCLUSIONS

There is a clear trend towards multi-disciplinary, multi-site research involving ethnographic observations and numerous user studies. Such research offers new insights into how the technologies we create can be used but also presents new methodological challenges. In this paper we have described a practical framework for tackling ethical and compliance issues. Our framework has been developed within the context of several years' practical study of the use of pervasive display systems. Such systems are inherently best studied "in the wild" and hence we consider our framework to be particularly relevant to the pervasive displays community. However, it is clear that other research areas will have to tackle similar issues (e.g., social networking research [10]) and we hope that our framework is useful to a broad class of researchers, in particular given the increased relevance of ethical processes in current [11] and future funding schemes, such as the EU's "Horizon 2020" program [12].

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# ANNEX

Examples to illustrate the documents available at the web site

## PD-Net Ethics Primer

### Introduction

This ethics primer is intended for PD-Net project members and provides an introduction to ethical issues in research involving studies and experiments with humans. It also outlines the ethical assessment process adopted in PD-Net.

Ethical guidelines on human subject experiments provide guidance on how to properly treat human subjects and their data. While computer science typically does not concern itself with experiments in the same way that, say, medicine or psychology does (i.e., directly experimenting upon individuals), many of our studies will ultimately collect and store information that may or may not be associated with individuals. This information may inconvenience or even threaten the physical and psychological well-being of test subjects, should it be used for unforeseen purposes or be shared with unintended recipients. For example, if usage measurements of how an employee uses work-related software would leak, his or her employer might learn of substandard performance, hidden attitudes, or detect obvious errors in conduct. By following the ethical principles set forth in this handbook, work in PD-Net should minimize potential threats to human subjects stemming from project-related user studies.

Use the table of contents below to locate relevant information in this document. Of particular interest is the PD-Net Ethical Assessment Process (page 4) and the fundamental Ethical Principles (page 4) that research within PD-Net follows.

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Figure 3: The Ethics Primer offers an introduction to ethical issues and is mandatory reading for new team members.

## Guide to Observational Studies

### A PD-Net Study Process Template

PD-Net conducts observational studies in public. Such studies must respect the privacy and psychological well-being of the individuals studied. Unless those observed give their consent to being observed, observational research is only acceptable in situations where those observed would expect to be observed by strangers. Additionally, particular care should be taken of local cultural values and of the possibility of intruding upon the privacy of individuals who, even while in a normally public space, may believe they are unobserved.

### Audio-Visual Recordings

In general, observations in public should avoid the use of audio-visual recordings, such as video recordings or voice recorders, unless all identifiable subjects have given their informed consent (i.e., filled out a consent form prior to the study). As this is hardly feasible in large public spaces, the use of video recordings in observational studies is severely limited. Several countries, notably Germany and Switzerland, place special protections on recording people, even in public, as part of their "personal rights" ("Persönlichkeitsrecht"). In such jurisdictions, people retain the "right to their own image" ("Recht am eigenen Bild") within part of copyright law (Urheberrecht). Exceptions under such laws are only public figures ("Personen der Zeitgeschichte"), people who accidentally appear in the background but are not the purpose of a recording ("Staffage"), and those in a crowd attending public events ("Menschenmengen").

### Picture Logs

Many of the restrictions regarding AV-recordings also apply to still pictures. However, individual pictures might allow researchers to better focus on the primary object of study (e.g., a poster wall). Pictures that do not show people might still require secure storage in case they contain personally identifiable information, such as phone numbers and names (e.g., from a poster board showing classifieds). In this case, the requirements for secure storage of PII as outlined in the PD-Net Study Process Template "Guide to Secure Data Storage" apply.

### Written notes

The preferred method for observational studies in public are (hand-) written notes. Notes avoid the risk of recording PII information, given that the recording researcher does not know the observed people personally, and no identifiable information is recorded. In most settings, such identifiable information is usually impossible to obtain solely from watching, e.g., a public space. In order to successfully record such observations, researchers are advised to run a pre-study identifying salient features that should be "recorded", and to use structured tables and forms, as well as coded identifiers to facilitate quick note taking.

<sup>1</sup>In Germany, e.g., „Gesetz betreffend das Urheberrecht an Werken der bildenden Künste und der Photographie (KUG) vom 9. Januar 1907 (RGBl. 7)" and the „Urheberrecht von 1965 (Urhg)"

Figure 4: The Observational Studies template outlines how data for field studies should be collected and processed.

## Guide to Obtaining Informed Consent

DRAFT EXAMPLE – FOR ILLUSTRATION ONLY

### A PD-Net Study Design Brief

Consent to participate in a research study should be understood as a process rather than an event [1]. Researchers should plan for and articulate the steps by which consent is initially obtained and the steps by which it is reviewed throughout the study. In order for participants to give meaningful consent, they should be able to understand the intent of the research, be clear about what they are being asked to do and if any risks are involved, and know how their information will be used.

### Enabling Informed Consent

Consent may be documented in many ways. Oral or implied consent are as legitimate as written consent, and in some contexts may even be more appropriate. The key idea is to go over the information verbally and document the process of gaining consent in field notes so as to leave a written trail. Even with oral consent, however, it is still reasonable to leave written material with the participant (e.g., an information letter).

Consent must always be in language that is understandable and not legalistic or too scientific, and the consent process should make room for questions, as appropriate to the research context. When a written-and-signed approach to consent is used, the information letter and consent form are best presented as one document.

The Information Letter should begin with an invitation to potential participants and should explain why they have been asked to participate. The body should provide a brief (i.e., a paragraph or two), plain-language description of the PD-Net project (examples in English can be found in Appendix B), the particular study that participation is sought for, and the nature of participation. An explanation of how key ethics issues—such as consent and confidentiality—will be handled, along with a discussion of risks and benefits, and compensation if any, should follow. The information letter should be written as if it was being sent from the researcher to the participant, that is, in the 2nd person. It should include an introduction of the researchers and their affiliations.

The Consent Form should include a brief summary of what will happen from the participant's perspective—without redundancy. It should note that the study has been explained to the participant, and the participant has had a chance to have his or her questions answered. The basic elements of consent, bulleted below, should be taken into account relevant regardless of process—whether written in hard copy, via e-mail, on the web, or presented verbally in person or over the phone. However, not all items are appropriate for all protocols, and some additional items may be useful on a case by case basis. Appendix A contains an example form.

### General Points

- Use letterhead of the department/organization undertaking the research
- The language level is appropriate to the age and reading level of the participant population
- Affiliation and contact information for the investigators and (where appropriate) research coordinator is included
- Participants are given a copy of the information letter to keep for their own

Figure 5: The Informed Consent template describes various ways of obtaining proper consent from study subjects.

## PD-Net Ethical Worksheet

This worksheet documents a particular experiment within PD-Net that is covered by one or more Study Process Templates (SPTs). It is used for documentation purposes and forms part of the corresponding deliverable in which this experiment took place. It helps researchers within PD-Net to ensure that all personal information collected and processed in PD-Net is treated in accordance with the project's ethical guidelines and the feedback from its ethical advisory board (EAB).

### 1 Study Information

#### 1.1 Study Title

Give a concise title to your study that describes the particular problem you are investigating in your experiment and/or field study.

Click here to enter text.

#### 1.2 Brief Description

Describe your experiment in a few sentences (no more than 3-4 sentences). The description should include the problem you are trying to address and the methods you are planning to use.

Click here to enter text.

#### 1.3 Planned Duration

How long (start, finish, duration) do you plan to run these experiments and/or field studies for?

Click here to enter text.

#### 1.4 Work Package

What PD-Net work package(s) does this work fall in?

Click here to enter text.

Figure 6: The Worksheet is the entry point for any new user study, linking to process templates and requiring researchers to reflect on their study design and data handling.