D1.5 Ethics Manual (Final)

File name	PuppyIR-D1.5-EthicsManualFinal-v1.0.doc
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Work package/task	WP1
Document status	Final
Version	1.0
Contractual delivery date	30/11/2010
Confidentiality	Public
Keywords	Ethics, user studies, children, data treatment, regulations, protocols, requirements
Abstract	The Ethics Manual of the PuppyIR project serves three purposes. Firstly, the Ethics manual is to be used in the initial stages of PuppyIR as reference and guide during design, planning and running of all user studies required for the specification, development and testing of PuppyIR tools. It is meant to be relevant to all researchers who plan to run user studies in order to gather feedback on newly developed tools. In general, it aims to ensure the appropriate level of engagement and commitment of researchers in conducting their studies with respect to ethical issues. The process and path suggested to follow in order to guarantee that the correct code of ethics is respected have in-built flexibility in order to accommodate for different local formal requirements in terms of procedures and practices. Secondly, the Ethics Manual can be used as a reference and guide during the establishment of a privacy policy for a specific PuppyIR tool. Finally, we pursue transparency in the way user studies will be performed and in the privacy aspects of PuppyIR.

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Executive Summary

This Ethics Manual of the PuppyIR project serves three purposes. Firstly, the Ethics manual is to be used in the initial stages of PuppyIR as reference and guide during design, planning and running of all user studies required for the specification, development and testing of PuppyIR tools. It is meant to be relevant to all researchers, who plan to run user studies in order to gather feedback on newly developed tools. In general, it aims to ensure the appropriate level of engagement and commitment of researchers in conducting their studies with respect to ethical issues. The process and path suggested to follow in order to guarantee that the correct code of ethics is respected have in-built flexibility in order to accommodate for different local formal requirements in terms of procedures and practices. Secondly, the Ethics Manual can be used as a reference and guide during the establishment of a privacy policy for a specific PuppyIR tool. Finally, with describing the legal framework we pursue transparency in the way user studies will be performed and in the privacy aspects of the PuppyIR.

This document has been prepared in collaboration with all partners involved in PuppyIR, in particular EKZ and UoS. Their experience in running user studies in accordance with the relevant ethics codes has been taken into account and in section 2 of this report care has been taken in order to ensure that their current practices, procedures and requirements are accounted for. It is envisaged that studies run by UoS researchers and other UK-based groups will follow a more formal path for approval, in accordance to their institution's and country's regulation; studies conducted by groups situated in other countries will follow a lighter implementation of the suggested protocol and path.

D1.5 starts with an overview of principles underlying the FP7 rules and guidelines in section 1. Zooming in on the requirements and regulations in the countries where PuppyIR experiments are going to take place (UK, the Netherlands, Germany), sections 2.1 and 2.2 describe the management and protection of personal data, and the involvement of young people in user studies. The regulations in Belgium and Spain, where two of the partners are situated, will be addressed briefly, although no user studies are foreseen in those countries.
A protocol to be followed in all PuppyIR user studies is presented in section 2.3. This protocol involves the documentation of measures taken for each user study to be conducted. The template structure designed for this purpose is largely generic, but also acknowledges some of the differences in local regulations.

For the monitoring of the proposed protocols, the consortium has established a PuppyIR Ethics Task Group (ETG), whose role is to advise and provide guidance and support during the preparation of user studies and to ensure that the protocols comply with the relevant code of practice. The group also has to approve the specification of the detailed protocol selected for application in a particular case before a user study is conducted.

Section 3 will discuss ethical and privacy considerations in the use of PuppyIR tools.
Section 3.2 addresses privacy issues of search engines. These issues led to a description of procedures to guarantee that experiments and online demonstration systems will always address ethical concerns regarding privacy and anonymity as described in section 3.3.

1 Introduction

This version of the Ethics Manual of the PuppyIR project consists of two major parts:

- Data protection and code of ethics in research and (section 2),
- Ethics and privacy in the use of PuppyIR tools (section 3).

Data protection and code of ethics in research

The first part of the Ethics manual describes regulations and requirements for running user studies in the countries where the PuppyIR consortium is planning to either run pilots or full evaluation experiments involving young users. As foreseen, user studies will take place in the UK, the Netherlands and Germany. The main objective of this ethics manual is to provide guidelines for the appropriate conduct in carrying out such user studies. The guidelines are supposed to respect the ethics issues presented in http://cordis.europa.eu/fp7/ethics_en.html [1], with particular attention to the ethical aspects of user studies involving young users as subjects of high vulnerability and variable levels of engagement according to age.

Two types of ethical issues related to the project's user studies to be conducted will be explored in this manual. The first ethical issue concerns the storing, management and use of the research data, in such a way that it guarantees privacy and anonymity according to local and European laws. All released research data should be accompanied by sufficient explanations, and a number of conditions should be met in order to prevent misuse. This topic will be further discussed below.

The second issue relates to the code of conduct relevant for the scenarios of use selected as part of WP1 and the various environments it covers: museum, school, home and hospital. It is essential to guarantee comfort and safety of children and guardians/professionals who take part in studies, as well as the security of their personal data (on preferences, profile and location), acquired during the evaluations.

PuppyIR will follow the guidelines of the European group on ethics in science and new technologies (see http://cordis.europa.eu/fp7/ethics_en.html).[1] These point to achieve a situation where subjects are exposed to "Minimum Risks, Fear, Pain and Distress", while achieving "Real and Direct Benefit". In our research context, this will be translated carefully, case by case, by avoiding any sense of frustration or "not being able to achieve a goal" in participants and making sure they have a pleasant and rewarding experience when interacting with new technology in an educational, yet fun-rich environment. All national legal and ethical requirements of the member states where the research is performed will be fulfilled.

PuppyIR will be running research intending to involve children and young people as respondents. In designing the protocol, inspiration has also been sought from the long-standing experience by a well-established UK children charitable organization such as Barnardos (see www.barnardos.org.uk/) and their statement of ethical research practice (http://www.bris.ac.uk/education/research/centres/creole/resources/ethics/barnados.pdf) [2] that describes how:

- young people should be involved as early as possible in the design, planning and piloting of research whenever possible.
- safeguards to minimize any inconvenience, disruption, intrusion, embarrassment, coercion or distress should be written into the research protocol.
- attention should be paid to ensuring that participation in research is a positive and rewarding experience. Where appropriate consideration should be given to suitable compensation.
- feedback on research findings should be provided to children and young people as part of acknowledging their contribution and seeking their views on outputs and dissemination.

- the informed consent of children and young people to participation in research should be actively and explicitly sought.
- information about the proposed research and the optional nature of participation should be provided in both oral and written form and presented in accessible language.
- attention should be paid to minimizing possible coercion from parents, teachers and other adults, and to minimizing the influence of peer pressure.
- young people should be encouraged to question researchers about the aims and methods of the research.
- written, or explicit, recorded consent should be obtained from research participants whenever possible.
- the consent of parents, or guardians should be routinely sought.

Section 2 of this manual will look into data protection briefly describing differences between the UK and the rest of Europe in terms of implementation. Section 3 will follow the same approach when looking into Code of Ethics and its implementation. The focus of both sections will be the current regulations, requirements and their implementations in the countries where user studies will take place: The Netherlands, where the user partners (EKZ and Museon) are based and UK and Germany as pilots with some British and German primary schools are foreseen.

Section 3 describes how the partners' protocols for ethics handling have been integrated into a common protocol for all project tests. Among others, the ethics protocol will specify which data are essential for the research and which should be excluded from retention. The protocol proposed involves the documentation of measures taken before the start of user study.
The template structure designed for this purpose is largely generic, but also acknowledges some of the differences in local regulations. An Ethics Task Group has been established that should approve the documentation before the start of a study. Its role and structure is outlined in section 3 as well.

Ethics and privacy in the use of PuppyIR tools
Section 3.1 describes some general privacy issues of search engines and implications for the PuppyIR novel tools. Therefore a statement on data protection and on how children will be protected from harmful data must be made for every novel PuppyIR tool. Section 3.2 describes what aspects need to be addressed in such a statement.

2 Data protection and code of ethics in research

2.1 Data protection

Data protection relates to the processing of personal data. Personal data is data that relates to a living individual who can be identified based on the data collected. The data types covered include both facts and opinions, and generally includes information regarding the intentions, aims and purposes of the data controller[1] towards the individual, also referred to as data subject. Processing relates to obtaining, recording, disclosing, or carrying out any operation on the information or data. It covers automatically processed or processable information.

For UK based studies, the collection, storage, disclosure and use of research data by researchers must comply with the Data Protection Act 1998 (http://www.legislation.gov.uk/ukpga/1998/29/contents). [3] Researchers should be aware of the risks of identification and breach of privacy and confidentiality posed by all kinds of information storage and processing, including computer and paper files, email records, photographic material, audio and videotapes and any other information in which an individual is named, or from which an individual could be identified. Research undertaken with users and participants should be premised upon a clear agreement regarding the use of confidential information.

The processing of personal data must comply with the 8 Data Protection Principles. In general terms, they require that:

1. personal data shall be processed fairly and lawfully (with specific requirements for 'sensitive personal data').
2. personal data shall be obtained only for one or more specified and lawful purposes, and shall not be further processed in any manner incompatible with that purpose or those purposes.
3. personal data shall be adequate, relevant and not excessive in relation to the purpose or purposes for which they are processed.
4. personal data shall be accurate and kept up to date.
5. personal data processed for any purpose or purposes shall not be kept for longer than is necessary for that purpose or those purposes.
6. personal data shall be processed in accordance with the rights of data subjects.
7. appropriate technical and organisational measures shall be taken against unauthorised or unlawful processing of personal data and against loss or destruction of, or damage to, personal data.
8. personal data shall not be transferred to a country or territory outside the European Economic Area, unless that country or territory ensures an adequate level of protection for the rights and freedoms of data subjects in relation to the processing of personal data.

For studies in The Netherlands, a similar approach and attention is required:

1. Researchers treat personal data according to Dutch law [4].
2. Personal data are treated confidentially. Personal data that can lead to the identification of a test-person will be separated from research data.
3. Researchers use personal data only for the (pre-defined) objectives they are collected for.
4. Personal data will not be given to third parties without a written consent of the test person and only for the purpose of scientific research.

[1] In this context, a data controller is the person who (either alone or jointly or in common with other persons) determines the purposes for which and the manner in which any personal data are, or are to be, processed.

5. If it is necessary to have a systematic database of identifiable personal data, the researcher must register this database with the Data Protection Authority (College Bescherming Persoonsgegevens), according to Dutch law [4,5,6,7,8].
6. Researchers should take appropriate technical and organizational measures to prevent loss of data or unauthorized access or unauthorized processing of data.

The same applies for studies in Germany:

1. The regulations of the German Data Protection Act apply (http://bundesrecht.juris.de/bdsg_1990/index.html) [9]
2. Any non-governmental institution of 10 or more members that collects personal data is required to nominate (a) data protection representative(s) who act(s) as a contact point between data collectors and test persons and ensure(s) adherence to current data protection legislation.
3. The collection of personal data requires explicit informed consent of the test person explaining the exact amount and type of data collected as well as its purpose.
4. Personal data will not be given to third parties without a written consent of the test person and only for the purpose of scientific research.
5. Data collection should be done parsimoniously. The amount and type of collected data should not exceed the requirements of the stated research goal.
6. In the case of publication of example cases the relevant data has to be anonymized in such a way that the test person can not be identified.
7. The test person has the right to
    - Inquire about the exact amount, type and origin of her/his personal data present
    - Receive a copy of any personal piece of information
    - Order the deletion of any desired personal piece of information about him/her

The difference between the Dutch, German and the British situation is in the implementation of the procedures for guaranteeing data protection that in UK are more formal. UoS, for example, acts as the 'data controller', and as such determines the purpose for which, and the manner in which, any personal data are processed. (http://www.strath.ac.uk/dataprotection/ for more details). All staff and students are required to adhere to the requirements of the current data protection legislation and the University Data Protection Policy. Formal requests and notices should be communicated to the University Data Protection Officer. In the event that contact is made directly with the department concerned, the department must ensure that any such formal requests are immediately forwarded to the University Data Protection Officer. At the same time, in order to provide researchers with flexibility departments are encouraged to use their discretion in deciding whether to allow data subjects to access their own personal data without using the formal mechanisms offered by the legislation.
This slight difference in implementation is taken into account in the protocol described in section 4, as this is flexible enough to allow for differences in terms of permissions and formal requirements.

Relevant regulations of other European countries
Regulations in Belgium (http://www.privacycommission.be/nl/legislation/national/#N10096) [10], France http://www.cnil.fr/fileadmin/documents/en/Act78-17VA.pdf [11], Spain (http://www.craig-edmonds.com/pdf/spanish-data-protection-law.pdf) [12], Austria (https://www.dsk.gv.at/site/6230/default.aspx) [13] are comparable to the regulations in the UK, Netherlands and Germany.

2.2 Code of Ethics in research

In this section, local regulations, requirements and practices are explored for countries where user studies are going to be conducted by the PuppyIR consortium members (e.g., The

Netherlands, UK and Germany). They are all in line with the principles and recommendations expressed under the Seventh Framework programme (FP7) in http://cordis.europa.eu/fp7/ethics_en.html [1], in particular those covering situations involving children and their vulnerability, and differences in terms of abilities due to age and development.

Current practices in the various countries differ: in the UK regulations have been implemented in a much more formal way. This obviously has an impact on how user studies will be designed at UoS and elsewhere in the UK. Cf. the end of this section.

In general the Code of Ethics and its implementation in terms of Code of Practice ensure that:

- research is designed and undertaken to ensure integrity and quality;
- research subjects (e.g. interviewees) are informed fully about the purpose, methods and possible uses of the research and what their participation involves;
- the confidentiality of information and participant anonymity is respected;
- involvement of research participants is voluntary; and
- research is independent, free of conflicts of interest or partiality.

When planning to run research in any of these countries researchers will have to consider that:

- the research will be designed and executed in line with relevant local directions;
- it is the responsibility of each researcher to ensure that every project is conducted in an ethical manner and all individuals working on the project under his or her supervision adhere to the same values;
- the acceptability of the research will be reviewed in light of the national ethical principles and when applicable institutional requirements by the Ethics Task Group (see section 4)
- researchers and their assistants will only execute tasks, which they are properly trained and prepared for
- research is done in suitable institutions
- when research takes place with subjects with specific problems, the researchers will investigate the problems in advance of the research.

Researchers

- Researchers take measures to ensure that the rights and the wellbeing of the subjects and others, who are involved in the research, will not be abused.
- For Scottish (such as those run by partners at University of Strathclyde and Glasgow) based studies, where the participants are under 18 years old or are deemed to be 'vulnerable' then all investigators must be checked through Disclosure Scotland[2] procedures before the investigation can commence. This could bring some difficulties in some of the investigations carried out. One particular difficulty relates to investigations that might involve access to pupils in a number of different schools. Each school/local authority requires a separate Disclosure Scotland check to be carried out before the investigation can commence. This is a time consuming exercise and can quite often delay the start of the project. However, investigators working in this area know that they have to allow time for these checks to be carried out, from 3 to 6 weeks.

Subjects or Test-persons

- Subjects (also called test-persons in this context) are expected to be young.
- Young subjects can be involved if the research is expected to lead to new scientific insights. This is in accordance with FP7 directions where benefits of this sort are seen as a valid motivation for involvement of children in user studies.

[2] Disclosure Scotland is in charge of running background checks for all members of University, researchers and students, planning to work with children or vulnerable subjects. For more information see: www.disclosurescotland.co.uk/

Recruitment

- Subjects will be freely recruited among relevant age groups via appropriate channels but recruitment will be open to all suitable subjects with no bias or coercion.
- Dependency of the potential test-persons or their representative may not influence consent in any way.
- The compensation given to test persons is in balance with the nature, scope and the purpose of the research.

Informed consent

Informed consent is required when the research involves children and personal data are collected.

- Prior to the execution of the research, the researchers will inform the subjects and/or their legal representatives about what they can expect from the investigation. This information will be given to the subjects and/or their legal representatives in the form of a letter. For Dutch studies this letter will comply with the directives of the Central Committee of Research Involving Humans [8]. Subjects will be informed in understandable language about the purpose and the procedures of the investigation. Information sheets are comprehensive and separate for parents/ legal representative and for children. Information sheets must be in accordance to the age of children. For British studies, UoS requires as defined in http://www.strath.ac.uk/ethics/ [14] that when available, a copy of the research commissioning letter - explaining the purpose and organisation of the evaluation - should be given/sent to subjects. Where a project website has been established, the subjects should be given the web address. Furthermore, in advance of the research, subjects should be given appropriate information on the nature of the research as follows (see also below):
  (i) the name(s) of the person(s) conducting the interview;
  (ii) the key questions/issues to be covered in the research;
  (iii) the expected duration of the subject's participation
  (iv) that confidentiality and anonymity of the interviewee will be maintained (they will not be quoted or otherwise identified in reports);
  (v) how information will be used for the study;
  (vi) that records may be kept for further or follow-up research by the PuppyIR project, but that they can decide not to allow this; and
  (vii) that they will be informed of the outcomes of the research by being notified when the Interim, Draft Final and/or Final Reports are published.
  (viii) information about who is organizing and funding the research;
  (iix) a description of any benefits to the subject or to others which may reasonably be expected from the research avoiding inappropriate expectations
  (ix) a reference to whom to contact for answers to questions about the research
  (x) the right to withdraw from the study at any moment
- While it is important for the evaluation to obtain accurate and detailed information, individual participants must not be pressured to participate in (any part of) the study.
- For children younger than 12 years, the legal representative of the child must sign the informed consent form. For children aged 12 or higher, both the child and the legal representative must sign the consent form. For British based studies see previous point on the necessity to run disclosure checks on all involved researchers.
- Researchers must inform any prospective subject that participation is voluntary and that any reason can be given to refuse or stop participation at any time. For UoS based studies, this consent should be recorded – whether given by email, letter, telephone or in person.
- Researchers inform the future subjects about important factors that their willingness to participate might influence (such as risks, discomfort or limitations on confidentiality).
- Researchers explain all questions to subjects. Researchers inform subjects about the reports they will get during the research.
- Subjects will have enough time and opportunities to read the information, to ask questions and to consider participation.

- Based on the information of the letter and the verbal information given by the researcher, the subject will be asked to participate in the research and sign the informed consent form. The consent form will contain the name of the research and the specific details of the information letter (date/version).
- The burden on subjects must be minimal, especially in case of children. Researchers provide an appropriate explanation for the children, based on their age group. In all cases, informed consent of the legal representative is compulsory.
- Researchers do not offer excessive or inappropriate financial or other incentives to recruit test persons.
- The amount of compensation should not influence the decision to participate.

Research protocol

The research protocol states how research will be run and how it will benefit users/subjects.

Acting of researchers

- During the investigation, researchers abide by the relevant national legislation and their professional code.
- Researchers do not use methods, which affect the dignity of subjects, or penetrate in their private life more than necessary for the intended purpose.
- Researchers comply to settlements, agreed with subjects. This applies to the agreements in the information letter, informed consent form and verbal agreements made before, during or after the investigation.
- Researchers do not mislead subjects about risks, discomfort, research procedures of the research.
- Prior to the research, the researchers inform subjects about the personal information they will receive after the investigation.
- When requested, researchers give the subjects all collected research data, so far as no personal identifiable data is released, which refers to other participants in the research. According to UoS regulation experts should maintain confidentiality and anonymity by ensuring that test person's feedback is not given to anyone outside the research team. The record of the feedback itself should also make a clear distinction between the factual information/opinions expressed by the test person and any interpretation of the evaluator. The record should also highlight any information provided by the test person as background or personal information which is not to be used in writing reports. Researchers report on this subject in a clear, comprehensive manner and try to correct obvious misconceptions that test persons can have after the research.
- Researchers give subjects the opportunity to obtain information about the nature, results and conclusions of the research. No personal data will be released. For UK studies, experts should maintain a secure record of all aspects of the fieldwork process, from the first approach made to test person to the writing up of the results. In practice, this means keeping copies of relevant correspondence, notes of phone calls, records of interviews etc. securely so that if the interviewee raises any questions at a later date, experts can demonstrate (for example) that they obtained informed consent or that they have a record of the interview.
- In general and across involved countries, the privacy of the subjects should be respected; personal data should be regarded as confidential. Personal data is to be kept separated from the research data see section 2 of this manual for more details.
- Researchers take care that the presentation of the research, in whatever form, is anonymous; in cases, perhaps apart from showing videos or pictures, which then should be added to the consent form.
- Survey data are retained until the objectives they are collected for are reached and the reporting is completed. For UoS data protection means: retaining records only for the period for which they are required for research purposes; utilising Strathclyde University (or other organisational) email accounts which have adequate virus protection (and avoiding use of home PCs / email accounts); ensuring storage in a safe place (password-protected in the case of electronic storage), with appropriate back-ups; taking care with the transport of data

(especially on laptops and memory sticks, where data should be made anonymous wherever possible); ensuring that data is not shared with another organisation unless approved by the project manager (and in accordance with the terms of Ethics Committee approval of the study); and disposing of data and equipment in ways that the data cannot be recovered.

For research run in the Netherlands all evaluation of scientific research is regulated by Dutch law [2, 3] and its implementation is left to researchers in terms of trust. The same is valid for German and Belgian regulations, very similar to the Dutch ones. They follow the same principles both for personal data management and protection, and for the ethics code of practice, individual institutions are free to choose how to implement these regulations.

When it comes to the British situation, and UoS in particular, it is now clear, looking at the various additions and extra requirements inserted in the previous list how the implementation of these principles is much more formal. As described at www.strath.ac.uk/secretariat/gmpt/ethics/ the regulations to follow are defined at university level. Each department is required to adhere to these regulations and implement internal mechanisms of control such as an Ethics Committee to advice, check and approve on each user study. This way of working is already in place at the department of Computer and Information Sciences where the PuppyIR researchers from UoS are based. Keeping this in mind, the next section suggests a process to be followed when designing user studies that would enable PuppyIR members to respect different existing practices while running user experiments in a flexible evaluation framework.

2.3 Protocol for PuppyIR User Studies

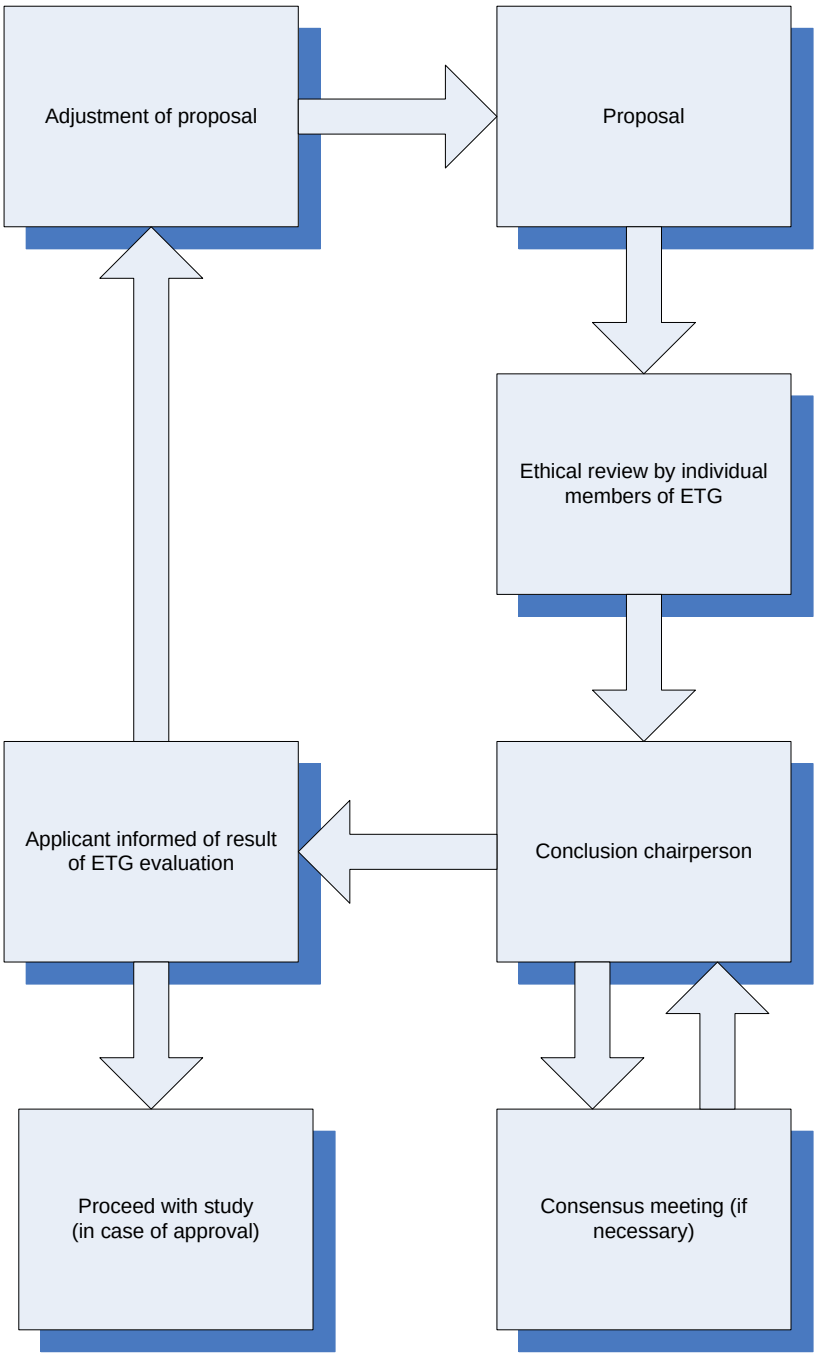
It is clear that, while following the same principles and philosophy, the implementation of British requirements is much more formal and detailed than the Dutch or German ones, starting from the existence of different levels of Ethics Committees (e.g. university, faculty and department) and the procedures to be followed in order to get any user study approved by the appropriate Ethics committee (i.e. submission of full and detailed plan of action, production of protocol of study with details on how users are to be invited, recruited, involved, and engaged in the study, plus description of how the data produced by the study is going to be managed and users' identity protected). Thus in running studies in the UK, PuppyIR researchers will fully adhere to the local code of practice and procedures. A lighter protocol for The Netherlands can be followed, and if applicable, in Germany. An effort will be made to ensure that this protocol does not interfere or delay any of the necessary user studies. For instance, once approval has been obtained for a line of study all its spin-offs will automatically be accepted too.
In order to ensure that user studies run in PuppyIR fully respect relevant code of ethics an Ethics Task Group is established to be responsible for the monitoring and updating of the ethics regulations (see appendix 1). The Ethics Task Group includes one member from all partners that are going to be involved in user studies plus the project coordinator.

Role of the Ethics Task group
The role of the ETG is to review plans for user studies in the light of the Ethics Manual and approve all the documentation describing each user study before it starts, following the procedure represented in the flow chart at the end of this section and here described.
Further the ETG is responsible for the monitoring of ethics regulations and updating of the ethics manual and for monitoring related issues in other initiatives.

Procedure
1. To guide the specification of the ethics measures taken within a specific PuppyIR user study, a template form (appendix 1) has to be filled in and submitted for approval by the PuppyIR Ethics Task Group. This template describes in detail how users will be invited and involved in study as well as how personal data will be dealt with, all in accordance to required regulations and internal code of practice. Letters of invitation and forms of consent (if applicable) are submitted as appendix.

2. The Ethics Task Group (or the partner assigned this task by the Task Group) will be responsible for the performance of a protocol check before the running of any user study.
3. The template-guided specification of the ethics measures should address the following details:
    - How and what type of participants will be obtained, in terms of expertise, age, gender, locations, equal ratio of … , access to users via …
    - Information to be provided to participants: e.g. Participants will be told that they are taking part in a user study to assess …..They will be told few more details about the study in terms of effort and tasks they will be presented with. Finally, they will be asked to complete a questionnaire, answer to an interview, etc…They will be told that the session is not expected to last more than …
    - How the informed consent of participants, and in the case of children, how the parent's permission is going to be obtained.
    - The task expected from participants: e.g.: Participants will be expected to take part in a learning session (material will be presented in either plain text or multimedia), followed by a post-test of 10 questions to test recall on the content of the material. This exercise will be repeated using a different set of material and alternating the use of plain text/multimedia. Finally, they will be asked to complete a questionnaire containing six questions about the experience. After a period of 4 weeks, participants will be requested to complete the same two post-test forms for a second time to test recall after time has elapsed.
    - How young users' vulnerability is going to be addressed
    - The necessity of involvement of young users and the benefits (direct and/or indirect) they will get from participation.
    - How the data will be stored: e.g. once the user study has been completed, the results will be copied into pre-prepared tables and stored on the hard drive of researchers/consortium PC/server/.
    - How the data will be processed: e.g. statistical analysis will be performed on the data.
    - Protocol for disposal of the data (how, when): e.g. 'Any material involved in the study (tests/questionnaires) will be completely anonymous, and will be destroyed once the results have been recorded.'
    - Measures taken to raise confidence that participants will not be involved under duress: e.g. provide information text including phrases such as 'It is a requirement that all volunteers are willing participants and feel no obligation to participate, so the researcher would not be at all offended if you would rather not take part.'
    - (For UK studies only) explanation of disclosure documents for all evaluator(s) to be in touch with young users.

Flow chart of the ethical review procedure



3 Ethics and privacy in the use of PuppyIR tools

3.1 Search engines and privacy

Search engines act as a gateway to Information. Search engines produce therefore implicitly, as a side effect of their implementation, various types of search log data that allow to study query characteristics and query reformulation strategies [15]. A large volume of research papers already exist and within PuppyIR the University of Twente has published a search log analysis using AOL data. As a consequence, we should guard ourselves against privacy concerns, as the development of online demonstration systems allows indirectly the same type of information to be acquired as the user studies discussed in section 2.
In general there must be a balance between privacy concerns and convenience for the user of a search engine. Thus, any online demo meant to gather user data should include a way to satisfy the requirement for informed consent, for example, by letting users fill out an online entry form before gaining access to the web interface. Users' age should be determined as accurately as possible, and when necessary, an online parental approval form should be sent to parent's email address for confirmation.

3.2 Privacy policy for PuppyIR tools

PuppyIR recognizes that privacy is important. For every novel PuppyIR tool a privacy policy, a statement on data protection and on how but children will be protected from harmful data will be made. This section describes what aspects need to be addressed in this policy and in statements. Further in the PuppyIR project online demonstrations and pilots are regarded in the same way as user studies, and therefore require a check by the ETG.

Information that is collected and how it is used:

- For the use of some products personal information is asked (such as name, email address, age and an account password). Information that is given is only asked if needed for the intended service and only used for the service that is given by the specific tool.
- Cookies allow storing such personal information locally at the client's computer. PuppyIR software prefers to avoid the use of cookies. In those cases where it does, the developers will take care that cookies are only transferred by employing Transport Layer Security (HTTPS protocol) to encrypt the connection.
- With every novel tool of PuppyIR detailed information is given about storage and processing of personal information and storage time.
- Sensitive information other than necessary for the service is not used unless a prior consent is obtained from the child and/or his/her legal representative.
- Log information: When you access any PuppyIR services, our servers automatically record information that your browser sends whenever you visit a website. These server logs may include information such as your web request, Internet Protocol address, the date and time of your request. These server logs are only used for research purposes**.**
- The right of a child or legal representative to object to, correct, choose and delete data related to his/her person

<u>Information sharing</u>
PuppyIR tools only share personal information with other companies or individuals outside of the PuppyIR project in the following limited circumstances: consent of the child and/or legal representative and only for research purposes and improvement of the service. Aggregated, non-personal information, such as the number of users who searched for a particular term, for

example, or how many users clicked on a particular website will be shared without consent. Such information does not identify an individual person.
Information will never be shared for commercial purposes.

Information security
Description of security measures to protect against unauthorized access to or unauthorized alteration, disclosure or destruction of data. We restrict access to personal information to PuppyIR employees and researchers. These individuals are bound by confidentiality obligations and may be subject to discipline, including termination and criminal prosecution, if they fail to meet these obligations.

Appropriateness of returned information
Searching the Internet presents risks that the information returned to the children is not appropriate. As in any other area of life, children are vulnerable and may expose themselves to danger, knowingly or unknowingly, when using and searching into the internet.

One of the key risks of using the internet is that children may be exposed to inappropriate material [16]. This may be material that is pornographic, hateful or violent in nature; that encourages activities that are dangerous or illegal; or that is just age-inappropriate or biased. Inappropriate material also includes extreme political, racist or sexual views for example, which are able to spread a distorted version of the world.

In the case of pornography and child abuse images, there is no doubt that the internet plays host to a large amount of legal and illegal material. Both parents and children must be informed.

One way to avoid these sites is by using children's search engines. These dedicated search engines try to avoid inappropriate content and offer "results that are deemed socially acceptable for a minor to view" [17].

SafeKids provides a list of children's search engines that exist on the Web today, each with its own unique way of filtering out questionable content. It is highly recommended that PuppyIR directs its search requests to those sites.

- Ask for Kids (www.askforkids.com)
- Yahooligans (www.yahooligans.com) will only display results hand picked from its own fully vetted listings.
- MSN for Kids (www.msn.co.uk/kids), mega-directory of about 5,000 sites selected by librarians as useful to and appropriate for, a younger audience.
- Cybersleuth Kids (www.cybersleuth-kids.com),
- FactMonster (www.factmonster.com),
- Lycos for Kids (www.lycos.com/kids) and Zoo (www.zoo.com).

Besides, many adult search engines have filtering options that make them safer for children's use. It is possible to set filter limits to narrow the parameters by which results are returned.

The SafeKids website reminds that **"**neither children's search engines nor filtering software should be used as a substitute for adult supervision. The only truly safe way for children to surf the 'Net is to do so with an adult present".

The following table indicates how to mitigate or take further actions when there is a risk of encountering inappropriate material.[18]

Hazard	Who might be harmed?	How to minimise the risk?	Further action needed to control the risk?
Children exposed to inappropriate material in the form of pornographic images	Children should feel safe and confident when using the internet, free from vulnerability, and not be made to feel awkward or uncomfortable. Children may suffer exposure to images of pornography, drug taking, or criminal activity.	Children and Parents or Child carers should be warned of possible risks. If relevant, training sessions around comfort zones and boundaries could be provided and trainers might take this opportunity to explore how comfortable children feel and how they respond in certain situations. **Communicate with your children about their experiences.** [19] Encourage your children to tell you if something they encounter on one of these sites makes them feel anxious, uncomfortable or threatened. Stay calm and remind your kids they are not in trouble for bringing something to your attention. Let them know you will work with them to help resolve the situation for a positive outcome.	Induction Training for Children and Parents. Adults in charge of the children should discuss with manager/supervisor and/or other senior colleagues as deemed appropriated. Share only "need to know" factual information. If needed refer to Children and Family services[3].

PuppyIR cannot give guarantees about the age appropriateness of returned information for those projects that search the open web (or simulate this on Clueweb). Rankings are made more age appropriate but these rankings are not perfect.

PuppyIR cannot give guarantees about protecting minors against racism and pornography for those projects that search the open web. This will partly be addressed by relying on used search engines API's directives to exclude inappropriate material from the ranking. The PuppyIR project has not implemented any tool to achieve this.

Other ethical aspects

PuppyIR tools will not use sponsored links.

[3] E.g. South West Grid for Learning Trust protocols www.swgfl.org.uk or the Child Exploitation Online Protection team www.ceop.gov.uk (last access 02/11/2010)

4 Conclusions

The ethics manual describes the current regulations, requirements and practices followed in the countries and institutes that will be involved in running of user studies for evaluating new interaction designs and tools developed by the PuppyIR consortium. While EU countries follow similar regulations and principles in line with those supported and required by the Seventh Framework programme (FP7), UK has the strictest practices in place. It is proposed that the consortium members adhere to the local regulations. For the monitoring of the proposed protocols, the consortium has established the PuppyIR Ethics Task Group (ETG), whose role is to advise during the preparation of user studies and to ensure that the protocols comply with the relevant code of practice. The group has to approve of the specification of the detailed protocol selected for application in a particular case before a user study is conducted. It is important to notice that the main aim of the ETG is to provide guidance and support to researchers when setting up and running their user studies. The ETG has to approve each user study based on the content of the following documents that describe in finer details how users will be approached, involved and engaged in each different circumstance:

- Template for protocol description.
- Information letter.
- Informed consent form.

A copy of the required template is provided in Appendix 1, and samples of consent forms are provided in Appendixes 2, 3 and 4, in English, Dutch and German.
We are glad to report that the presence of the ETG, even at this early stage, has already had a positive impact on our consortium, as it contributed to raise and further explore some very poignant discussions on how to run user studies online while maintaining required standards and respecting relevant regulations.

5 References

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[13] The Austrian Data Protection Act (https://www.dsk.gv.at/site/6248/default.aspx). Last visited on 30th November 2010.

[14] Code of Practice on investigations involving human beings. University of Strathclyde. http://www.strath.ac.uk/media/committees/ethics/Code_of_Practice_Oct_2009.pdf. Last visited on 30th November 2010.

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Appendix 1: PuppyIR ETG Approval Request Form

Name of the user study
PuppyIR partners involved
Main investigator/ contact person
Goal of the user study
Method
How are potential participants going to be involved in the study?
What are the characteristics of the participants? (e.g. age, gender …..)
What measures will be taken to address the young participant's vulnerability?
What is the necessity of involvement of young users and what are the benefits (direct and/or indirect) they will get from participation?
How will informed consent be obtained?
What tasks are expected from participants?
What data will be collected for the study?
How will the data be stored?
How will data be processed?
What measures will be taken to guarantee privacy of the test persons?
What will be done with the data after processing?

Please attach all relevant documentation e.g. information letter, informed consent etc. For UK studies only attach all explanation of disclosure documents for all evaluator(s) to be in touch with young users.

Appendix 2: Informed Consent Form (English version)

PuppyIR

Study of the search behaviour of children for the development of information services for children

INFORMED CONSENT

www.puppyir.eu

Background
The PuppyIR-study is carried out on *location*.
The study complies to Dutch and European law and the ethical principals that are described in the Ethics Manual that was composed especially for the PuppyIR project.

Aim of the study
The aim of the study is ……
We study children aged .. to .. years of age.
The ultimate goal is the development of an access to information based on the behaviour and need of children.

Who can participate?
All children between .. and .. years of age and *other conditions*

What is expected of your child?
Description of the study

What will be done with the questionnaires / test results/ other data?
Questionnaires
Questionnaires will be used to collect information about …….
Questionnaires are anonymous and will be destroyed when the results are processed.
Logfiles
Logfiles are used to record and analyse all operations of your child on the computer. This gives information about the way children look for information.
Personal data
Personal data will be handled confidentially. Personal data that can identify your child will be stored separately from results from the study. Personal data is never handed to other parties and will only be used in this study.

What happens if you withdraw your child from the study?
If you want to withdraw your child from the study you can do so at any moment and without explanation. You are not obligated to let your child complete the study. Although we hope this is your intention. If you decide to withdraw your child from the study this will not in any way influence …….. We request you to communicate your decision for withdrawal to *name* as soon as possible.

PuppyIR Informed Consent
Project Name: PuppyIR: An open source environment to construct information services for children.

Name of the participant: ……....
Number: …….
Date (dd/mm/yyyy): ……..

We/ I, as legal guardian, declare that:

- Mr/mrs ……gave us/me a copy of the information brochure and that he/she explained to us/me the study and the aim of the study.
- Mr/mrs ……..gave us/me the opportunity to ask questions about the study. He/she explained to us that we are free to withdraw our/my child from the study at any moment.
- We/I have read the information brochure and understood everything that is explained.
- We/ I consent that our/my child participates in the study.
- We/ I give permission to contact us again in the future.

Legal guardian

Place	Date (dd/mm/yyyy)	Signature

Researcher

Place	Date (dd/mm/yyyy)	Signature

Appendix 3: Informed Consent Form (Dutch version)

PuppyIR

Onderzoek naar zoekgedrag bij kinderen ten behoeve van de ontwikkeling van een zoeksysteem voor kinderen.

INFORMED CONSENT

www.puppyir.eu

Onderzoekskader

Het PuppyIR-onderzoek wordt uitgevoerd op *locatie*
Het onderzoek voldoet aan de Nederlandse en Europese regelgeving en ethische principes van onderzoek zoals zijn beschreven in de ethische handleiding die ten behoeve van dit onderzoek is opgesteld.

Doel van het onderzoek
Het onderzoek heeft als doel ……
We onderzoeken dit bij kinderen in de leeftijd van … tot en met …jaar.

Het uiteindelijke doel is de ontwikkeling van toegang tot informatie die gebaseerd is op het gedrag en de behoefte van kinderen.

Wie kan er meedoen?
Alle kinderen van … tot en met … jaar *en andere criteria*

Wat wordt er van uw kind verwacht?
Moet per onderzoek worden ingevuld.

Wat doen we met de vragenlijsten/testen/andere vastgelegde gegevens?
Vragenlijsten
Vragenlijsten worden gebruikt om informatie in te zamelen over …….
Vragenlijsten zijn anoniem en zullen worden vernietigd als de resultaten zijn verwerkt.
Logfiles
Logfiles worden gebruikt om alle handelingen die u kind verricht op de computer vast te leggen en te analyseren. Dit geeft inzicht in de manier waarop kinderen zoeken naar informatie.
Persoonlijke gegevens
Persoonlijke gegevens worden vertrouwelijk behandeld. Persoonlijke gegevens waarmee een kind kan worden geïdentificeerd worden gescheiden bewaard van gegevens die uit het onderzoek naar voren zijn gekomen. Persoonlijke gegevens worden nooit aan anderen gegeven en alleen gebruikt in het kader van dit onderzoek.

Wat gebeurt er als u wilt stoppen met het onderzoek?
Indien u de deelname van uw zoon/ dochter tijdens het onderzoek wilt stoppen kunt u dat op ieder moment doen, zonder daarvoor een reden aan te geven. U bent niet verplicht om uw zoon/ dochter het onderzoek helemaal te laten afmaken, we hopen echter wel dat dat uw uitgangspunt is. Indien u besloten heeft om uw zoon/ dochter het onderzoek niet te laten afmaken, zal dit besluit zijn/haar medische behandeling en/of bejegening in het Emma Kinderziekenhuis niet beïnvloeden. Wij verzoeken u om uw besluit zo spoedig mogelijk te melden aan ……..

PuppyIR Informed Consent

Naam project: PuppyIR: An open source environment to construct information services for children.

Naam deelnemer: ……...
Nummer: …….
Datum (dd/mm/jjjj): ……..

Hierbij verklaar/verklaren ik/wij als wettelijke vertegenwoordiger(s) dat:

- Dhr/ mw ……mij/ons een kopie heeft gegeven van de informatiebrochure en mij/ons de opzet en het doel van het onderzoek volledig heeft uitgelegd.
- Dhr/mw ……..mij/ons de gelegenheid heeft gegeven om vragen te stellen over het onderzoek. Hij/zij heeft mij/ons uitgelegd dat ik/wij vrij ben/zijn om mijn/ons kind op elk moment uit het onderzoek terug te trekken.
- Ik/wij alles dat is uitgelegd begrepen heb/hebben en de informatiebrochure heb/ hebben gelezen.
- Ik/wij erin toestemmen om mijn/ons kind deel te laten nemen aan dit onderzoek.
- Ik/wij * toestemming geef /geven om mij/ons in de toekomst na het einde van deze studie nogmaals te benaderen.

Wettelijke vertegenwoordiger(s) van de deelnemer

Plaats	Datum (dd/mm/jjjj)	Handtekening

Onderzoeker

Plaats	Datum (dd/mm/jjjj)	Handtekening

Appendix 4: Informed Consent Form (German version)

PuppyIR

Eine Studie des Suchverhaltens von Kindern zur Entwicklung kindgerechter Informationsdienste

EINVERSTÄNDNISERKLÄRUNG

www.puppyir.eu

Hintergrund
Die PuppyIR-Studie wird im *Position* in Amsterdam durchgeführt.
Die Studie unterliegt deutschem und europäischem Recht, sowie den ethischen Grundsätzen, die im speziell für PuppyIR zusammengestellten Ethikleitfaden beschrieben werden.

Ziel der Studie
Das Ziel der Studie ist ……
Wir studieren Kinder im Alter von … bis … Jahren.
Das Ziel ist die Entwicklung eines Informationszugangs basierend auf dem Verhalten und den Bedürfnissen von Kindern.

Wer kann teilnehmen?
Alle Kinder im Alter von … bis …Jahren *und andere Bedingungen*

Was wird von Ihrem Kind erwartet?
Beschreibung der Studie

Was wird mit den Fragebögen / Testergebnissen / anderen Daten geschehen?
Fragebögen
Fragebögen werden genutzt, um Informationen über ……..... zu sammeln.
Fragebögen sind anonym und werden nach Verarbeitung der Ergebnisse vernichtet.
Logdateien
Logdateien werden benutzt um alle Aktivitäten Ihres Kindes am Computer aufzuzeichnen. Dies gibt Aufschluss über das Suchverhalten von Kindern.
Persönliche Daten
Persönliche Daten werden vertraulich behandelt. Persönliche Daten, die Ihr Kind identifizieren können, werden gesondert von den Ergebnissen der Studie gespeichert. Persönliche Daten werden niemals an Dritte weitergegeben und ausschließlich für diese Studie verwendet.

Was geschieht, falls Sie Ihr Kind aus der Studie entfernen?
Sie können Ihr Kind jeder Zeit und ohne Angabe von Gründen aus der Studie entfernen. Sie sind nicht verpflichtet Ihr Kind die Studie abschließen zu lassen. Wir hoffen jedoch, dass Sie dies tun werden. Falls Sie sich entscheiden Ihr Kind aus der Studie zu entfernen, wird dies in keiner Weise seine (medizinische) Behandlung im Emma Kinderkrankenhaus AMC beeinflussen. Wir bitten Sie, Ihre Entscheidung, Ihr Kind von der Studie zu entfernen, umgehend …..... mitzuteilen.

PuppyIR Einverständniserklärung

Name der Studie: PuppyIR: An open source environment to construct information services for children.

Name des Teilnehmers: ……....
Nummer: ……
Datum (tt/mm/jjjj): ……..

Sind die Eltern verheiratet und die Erziehungsberechtigten des Teilnehmers?
Ja/Nein*
Ja → Beide Elternteile müssen dieses Formular unterschreiben.
Nein → Die erziehungsberechtigte Person muss dises Formular unterschreiben. Im Falle geteilter Erziehungsberechtigung müssen beide Erziehungsberechtigten das Formular unterschreiben.

Wer ist der Eziehungsberechtigte des Teilnehmers? Vater/ Mutter/ sonstige*

Im Falle sonstiger Erziehungsberechtigter: Wer ist der Erziehungsberechtigte des Teilnehmers?
……

Wir/ Ich bestätigen, dass:

- Herr/Frau ……. uns/mir ein Exemplar der Informationsbroschüre gab und uns/mir die Studie und das Ziel der Studie erklärte.
- Herr/Frau …….. uns/mir die Möglichkeit gab, Fragen über die Studie zu stellen. Er/Sie informierte uns/mich über die Möglichkeit, unser/mein Kind jederzeit aus der Studie zu entfernen.
- Wir/Ich haben die Informationsbroschüre gelesen und ihren Inhalt verstanden.
- Wir/Ich stimmen der Teilnahme unseres Kindes an der Studie zu.
- Wir/Ich willigen ein zu einem späteren Zeitpunkt erneut kontaktiert zu werden.

Erziehungsberechtigter des Teilnehmers

Ort	Datum (tt/mm/jjjj)	Unterschrift

Studienerheber

Ort	Datum (tt/mm/jjjj)	Unterschrift