Integrated intelligent LEARNing environment for Reading and Writing

D1.2 – ILearnRW's Ethics and Information Security Manual

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Abstract	This document focuses on the use of personal/ sensitive in ILearnRW. More specifically, it addresses: – Legislation Governing Ethical Issues and the Collection of Personal Data – Ethics Issues in Research – Use of Personal Data in ILearnRW – Information Security Issues
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Project information

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1. Introduction

The aim of the ILearnRW project is to contribute towards a move away of traditional assistive software which uses a computer simply as an alternative to pen and paper and develop next generation learning software which uses a computer to facilitate the learning process for children with dyslexia and/or dysorthographia.

The ILearnRW system builds and maintains individual profiles for each child (*User Modeling*). The profile should include, among others, the type of dyslexia and the errors the user is most likely to make. The interaction of a child with the learning environment should be based on a *teaching strategy* that supports the individual user in fulfilling his / her specific learning goals.

To improve its usability the ILearnRW system supports *classification of learning material*. Content classification must be a major component in any content management system. To think about it, a tutor helping a child to learn reading / writing always selects appropriate learning material based on the child's needs and capabilities. Additionally, the system produces and maintains an *on-line resource bank*. Coherent collections of data which support specific teaching strategies should be accessible to learners and educators.

Personalized content presentation is also an important feature of the system. If we know the errors the user is likely to make, we can enrich the text presentation with visual cues by combining highlighting, text-reformatting and word segmentation. In addition, the type of dyslexia should also influence the presentation.

Engaging learning activities for children are also provided by the ILearnRW environment. High degree of learner engagement is sought in any learning activity. To achieve this goal, we integrate learning activities into serious games. A creative game scenario, coupled with a positive reinforcement mechanism, will extend child's engagement.

Furthermore, the system offers the functionality of the *evaluation of learning*. When a game is coupled with a game usage logging mechanism, data collected related to the user's actions may lead to a quantitative assessment of learning.

During the execution of project, in order to test and train the software developed, as well as to evaluate its usefulness in an accommodative educational environment, we will need to collect and store personal / sensitive data, concerning children. Thus, ethical issues concerning the collection and use of these data must be considered. The main objective of this document is to define the way personal / sensitive data will be collected and used, according to the European and national legislations.

2. Legislation Governing Ethical Issues and the Collection of Personal Data

The operation of the ILearnRW project with respect to the processing of personal data conforms to the requirements of the Directives of the EC and the National Laws of the Member States concerning the protection of individuals with regard to the processing of personal data and the protection of privacy. These Directives are:

- Directive 95/46/EC[1] of the European Parliament and of the Council of 24 October 1995 concerning the protection of individuals with regard to the processing of personal data and on the free movement of such data.
- Directive 2002/58/EC[2] of the European Parliament and of the Council of 12 July 2002 concerning the processing of personal data and the protection of privacy in the telecommunications sector.
- Directive 2006/24/EC[3] of the European Parliament and of the Council of 15 March 2006 on the retention of data generated or processed in connection with the provision of publicly available electronic communications services or of public communications networks and amending Directive 2002/58/EC

The principles of the above Directives have been incorporated into the legislation of all countries involved in data collection in the framework of the ILearnRW project. Specifically,

In UK, the Data Protection Act 1998 came into force on 1 March 2000. It is concerned with the rights of individuals to gain access to personal information held about them by an organisation or individual within it, and the right to challenge the accuracy of data held. The terms of the Act relate to data held in any form, including written notes and records, not just to electronic data.

In the UK, it is a requirement to register as a Data Controller (DYSACT is such a Data Controller) with the Information Commissioner and his staff whose remit is to ensure that organisations that are processing data are doing so in line with the obligations that are placed upon them by the various pieces of legislation such as: the Data Protection Act, Freedom of Information Act, and the Privacy and electronic Communications Regulations.

In addition, in the UK, the Children Act 2004 and the Safeguarding Vulnerable Groups Act 2006 are applicable. The Children Act 2004 provides the legal basis for how social services and other agencies deal with issues relating to children. Guidelines have been laid down so that all individuals who are involved in the looking after children, be it in the home, the work place, school or other locale are aware of how children should be looked after in the eyes of the law. The Children Act 2004 was designed with guiding principles in mind for the care and support of children.

The Safeguarding Vulnerable Groups Act 2006 is designed to implement new and more stringent ways in which to carry out checks on those individuals who wish to work with children, the elderly or people who are classed as being in positions of vulnerability. The act gives employees new powers - in conjunction with those bodies who oversee the checking of potential new employees - to help confirm the safety and reliability of those individuals who wish to work with those who fall under the auspices of the Safeguarding Vulnerable Groups Act. The act also looks at how bodies such as the Criminal Records Bureau (CRB) carry out their tasks which include providing basic and enhanced disclosures

[1] http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:1995:281:0031:0050:EN:PDF
[2] http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:32002L0058:en:HTML
[3] http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2006:105:0054:0063:EN:PDF

for potential employees and employers and deals with how the system can run more efficiently and with tighter restrictions than are currently in place.

In Greece, the European Directives have been incorporated into

- Personal Data Protection Act, 2472/97[4],
- Data Protection Authority, Regulations 408[5], 1/99[6], concerning the notification of subjects about processing personal data,
- Act 3471/2006[7] concerning the processing of personal data and the protection of privacy in the telecommunications sector as amended by Acts 3783/2009, 3917/2011 and 4070/2012.

For the purposes of the Personal Data Protection Directive 95/46/EC:
(a) 'personal data' is any information relating to an identified or identifiable natural person ('data subject'); an identifiable person is one who can be identified, directly or indirectly, in particular by reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, cultural or social identity;
(b) 'processing of personal data' ('processing') is meant any operation or set of operations which is performed upon personal data, whether or not by automatic means, such as collection, recording, organization, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, blocking, erasure or destruction;

According to the Personal Data Protection Directive 95/46/EC and the corresponding Personal Data Protection Acts of the Member States personal data should:

- be obtained and processed fairly and lawfully and not be processed unless certain conditions are met;
- be obtained for a specified and lawful purpose and not be processed in any manner incompatible with that purpose;
- be adequate, relevant and not excessive for those purposes;
- be accurate and kept up-to-date;
- not be kept for longer than is necessary;
- be processed in accordance with the data subject's rights;
- be kept safe from unauthorized access, accidental loss or destruction;

Under the same legislation, the processing of special categories of data ("sensitive data"), such as personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, and the processing of data concerning health or sex life, is prohibited. This prohibition may not apply if the data subject has given his/her explicit consent to the processing of those data, except where the laws of the Member State provide that the prohibition may not be lifted by the data subject's giving his/her consent. Additionally, subject to the provision of suitable

[4] http://www.dpa.gr/pls/portal/docs/PAGE/APDPX/LAW/NOMOTHESIA%20PROSOPIKA%20DEDOMENA/%CE%9DOMOTHESIA%20PROSOPIKA%20DEDOMENA_GREEK/2472_97_NOV2011_FINALVERSION.PDF
[5] http://www.dpa.gr/pls/portal/docs/PAGE/APDPX/LAW/NOMOTHESIA%20PROSOPIKA%20DEDOMENA/FILES/%CE%91%CE%A0%20408_1998.DOC
[6] http://www.dpa.gr/pls/portal/docs/PAGE/APDPX/LAW/NOMOTHESIA%20PROSOPIKA%20DEDOMENA/FILES/KAN%20%CE%A0%CE%A1%CE%91%CE%9E%201_1999.DOC
[7] http://www.dpa.gr/pls/portal/docs/PAGE/APDPX/LAW/NOMOTHESIA%20PROSOPIKA%20DEDOMENA/%CE%9DOMOTHESIA%20PROSOPIKA%20DEDOMENA_GREEK/3471_06_MAY2012FINAL.PDF

safeguards, the Directive as well as the national laws of the Member States, for reasons of substantial public interest, lay down exemptions in the above prohibition.

In Greece, the collection and processing of sensitive data, is allowed only when the Data Protection Authority has granted a permit to the Controller for the collection and processing of sensitive data, as well as for the establishment and operation of the relevant file, upon request of the Controller (Controller is the natural or legal person, public authority, agency or any other body which alone or jointly with others determines the purposes and means of the processing of personal data).

3. Ethics Issues in Research

3.1. Guiding Ethical Principles

The purpose of this paragraph is to present the principles and procedures that will guide and ensure the ethical conduct of research in the ILearnRW project. Although codes, policies, and principals are very important and useful, like any set of rules, they do not cover every situation that arises in research, they often conflict, and they require considerable interpretation. It is therefore important for researchers to learn how to interpret, assess, and apply various research rules and how to make decisions about how to act in various situations.[8]

The approach taken is to guide and evoke thoughtful actions based on fundamental ethical principles. The principles that follow are based on statements from the international community.[9] The principles have been widely adopted by diverse research disciplines. As such, they express common standards, values and aspirations of the research community.

Respect for Human Dignity: The cardinal principle of modern research ethics, as discussed above, is respect for human dignity. This principle aspires to protecting the multiple and interdependent interests of the person – from bodily to psychological to cultural integrity. This principle forms the basis of the ethical obligations in research that are listed below.

In certain situations, conflicts may arise from application of these principles in isolation from one another. Researchers must carefully weigh all the principles and circumstances involved to reach a reasoned and defensible conclusion.

Respect for Free and Informed Consent: Individuals are generally presumed to have the capacity and right to make free and informed decisions. Respect for persons thus means respecting the exercise of individual consent. In practical terms within the ethics review process, the principle of respect for persons translates into the dialogue, process, rights, duties and requirements for free and informed consent by the research subject.

Respect for Vulnerable Persons: Respect for human dignity entails high ethical obligations towards vulnerable persons – to those, whose diminished competence and/or decision-making capacity make them vulnerable. Children, institutionalized persons or others who are vulnerable are entitled, on grounds of human dignity, caring, solidarity and fairness, to special protection against abuse, exploitation or discrimination. Ethical obligations to vulnerable individuals in the research enterprise will often translate into special procedures to protect their interests.

Respect for Privacy and Confidentiality: Respect for human dignity also implies the principles of respect for privacy and confidentiality. In many cultures, privacy and confidentiality are considered

[8] *The* Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans *(TCPS)* http://www.pre.ethics.gc.ca/eng/index/

[9] The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research. *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research.* Washington, DC, 1979.
Council for International Organizations of Medical Sciences, *International Ethical Guidelines for Biomedical Research Involving Human Subjects.* Geneva, 1993.
UNESCO, *Ethical Guidelines for International Comparative Social Science Research in the Framework of M.O.S.T. (Management of Social Transformation).* Paris, 1994.
The Research Council of Norway, *Guidelines for Research Ethics in the Social Sciences, Law and the Humanities.* Oslo, 1994.

fundamental to human dignity. Thus, standards of privacy and confidentiality protect the access, control and dissemination of personal information. In doing so, such standards help to protect mental or psychological integrity. They are thus consonant with values underlying privacy, confidentiality and anonymity respected.

Respect for Justice and Inclusiveness: Justice connotes fairness and equity. Procedural justice requires that the ethics review process have fair methods, standards and procedures for reviewing research protocols, and that the process be effectively independent. Justice also concerns the distribution of benefits and burdens of research. On the one hand, distributive justice means that no segment of the population should be unfairly burdened with the harms of research. It thus imposes particular obligations toward individuals who are vulnerable and unable to protect their own interests in order to ensure that they are not exploited for the advancement of knowledge. History has many chapters of such exploitation. On the other hand, distributive justice also imposes duties neither to neglect nor discriminate against individuals and groups who may benefit from advances in research.

Balancing Harms and Benefits: The analysis, balance and distribution of harms and benefits are critical to the ethics of human research. Modern research ethics, for instance, require a favourable harms-benefit balance – that is, that the foreseeable harms should not outweigh anticipated benefits. Harms-benefits analysis thus affects the welfare and rights of research subjects, the informed assumption of harms and benefits, and the ethical justifications for competing research paths. Because research involves advancing the frontiers of knowledge, its undertaking often involves uncertainty about the precise magnitude and kind of benefits or harms that attend proposed research. These realities and the principle of respect for human dignity impose ethical obligations on the prerequisites, scientific validity, design and conduct of research.

Minimizing Harm: A principle directly related to harms-benefits analysis is non-maleficence, or the duty to avoid, prevent or minimize harms to others. Research subjects must not be subjected to unnecessary risks of harm, and their participation in research must be essential to achieving scientifically and societally important aims that cannot be realized without the participation of human subjects. In addition, it should be kept in mind that the principle of minimizing harm requires that the research involves the smallest number of human subjects and the smallest number of tests on these subjects that will ensure scientifically valid data.

Maximizing Benefit: Another principle related to the harms and benefits of research is beneficence. The principle of beneficence imposes a duty to benefit others and, in research ethics, a duty to maximize net benefits. The principle has particular relevance for researchers in professions such as social work, education, health care and applied psychology. As noted earlier, human research is intended to produce benefits for subjects themselves, for other individuals or society as a whole, or for the advancement of knowledge. In most research, the primary benefits produced are for society and for the advancement of knowledge.

3.2. A Subject - Centred Perspective

Research subjects contribute enormously to the progress and promise of research in advancing the human condition. In many areas of research, subjects are participants in the development of a research project and collaboration between them and the researcher in such circumstances is vital and requires nurturing. Such collaboration entails an active involvement by research subjects, and ensures both that their interests are central to the project or study, and that they will not be treated simply as objects.

A subject-centred approach should, however, also recognize that researchers and research subjects may not always see the harms and benefits of a research project in the same way. Indeed, individual subjects within the same study may respond very differently to the information provided in the free

and informed consent process. Hence, researchers must strive to understand the views of the potential or actual research subjects.

In this context, researchers should take into account that potential subjects who are asked to participate in research by, for example, their caregiver, teacher or supervisor may be overly influenced by such factors as trust in the researcher or the hope for other goals, more than by assessment of the pros and cons of participation in the research. A patient may hope for a cure from an experimental drug, an employee for better working conditions, a student for better marks. This places extra demands on the researcher for accuracy, candour, objectivity and sensitivity in informing potential subjects about proposed research.

4. Use of Personal Data in ILearnRW

The ILearnRW project will involve children of primary school age with dyslexia and or dysorthographia, two forms of learning difficulties. During the course of the ILearnRW project personal data need to be collected, processed and stored. Based on the purpose, for which the data are collected, the data collection, processing and storage activities of ILearnRW project can be divided into the following phases:

1. User Requirements Analysis: children may participate in interviews during the "user requirement acquisition phase". Since the children are underage, they cannot give consent and, thus, consent forms have to be obtained by their parents/guardians.

2. User Modeling/ Serious Games: a profile will be defined for each user of the ILearnRW system. The profile will be based on a model which will include a general classification of the types of reading or spelling errors the user usually makes. During the development of user models that will be used in serious games, several children will be asked to play games and their actions/responses will be recorded.

3. Evaluation of ILearnRW: in the context of this project, the ILearnRW software will be operated in different settings (at class, at home, with the guidance of a tutor/parent, or unsupervised). Children will experiment for a long period of time with the ILearnRW system. The children's profiles may be updated by the ILearnRW system in order to monitor progress and to provide them the most suitable learning material in future sessions. Data will be recorded, stored and analysed in order to assist the evaluation of ILearnRW system and, possibly, to support finding relevant to research in dyslexia.

As part of its project management, ILearnRW will include the constitution and functioning of the Ethics Advisory Board and the establishment of the Project's Ethics and Information Security Policy. The Ethics Advisory Board will implement and manage the ethical and legal issues of all procedures in the project. The Project's Ethics Policy will be documented in an Ethics and Information Security Manual (ethics code of conduct of research), leading to the recognition of key ethical and legal issues (i.e. storage, transmission, use of the users' localization and personal data in project deliverables and publications, ethical use of tools and the development of a relevant project policy towards resolving these issues).

Members of the Ethics Advisory Board for the ILearnRW project are Prof. Antonios Symvonis (NTUA), Prof. Barry Beggs (LBUS), and Prof. Grammati Pantziou (external member). Prof. Symvonis and Prof. Pantziou are Members of the Greek Data Protection Authority Board and are familiar with European and Greek legislation related to data protection issues, while Prof. Beggs is familiar with UK data protection legislation. Note that no person affiliated with the partners that will run the evaluation (DYSACT, EPIRUS) is member of the Ethics Advisory Board.

4.1. User Requirements Analysis

An expert-centred approach will be employed during the development of user requirements. Speech and Language professionals and teachers / tutors are considered to the experts. When appropriate, a user-centred approach will be also employed in this task. Since the users of the ILearnRW system are children of primary school age they are not capable of designing their own learning goals. However, their input on what makes a learning experience relevant, engaging or meaningful is critical. If children with specific learning difficulties (dyslexia and/or dysorthographia) participate in the

acquisition of ILearnRW's user requirements consent will be obtained from their parents/legal guardians.

4.2. User Modeling/ Serious Games

Not all children with dyslexia have the same type of dyslexia. The reading impairment of some may be classified as surface dyslexia, while for others it is classified as developmental dyslexia, or deep dyslexia. As a consequence, not all children make the same reading errors and, in addition, even if they make the same type of reading errors the severity may be different. The same applies to spelling disorders (dysorthographia). In an intelligent learning system, a profile for each learner should be built. The profile, among other things, should include the type of dyslexia, the error types the user is likely to make and their severity, the learner's age and cognitive age, as well as information related to the learning history and progress during the usage of the system.

The users' profiles are likely to be stored in a central server[10], so as each child to be able to use the ILearnRW software on a different PC (in a class or at home). The learners' profiles will have to be updated during the use of ILearnRW and to reflect the learner's acquired skills and difficulties. Almost everything is the learning environment will be "profile-sensitive", that is, its behavior will depend on it. The presentation of the reading material will depend on the user's profile. The same holds for the selection of the appropriate teaching strategy, the content classification, the playing experience during a serious game, the search of the on-line resource bank.

An authentication mechanism (most likely the use of a login-name and a password) will be used in order (a) to allow access to the system and (b) to ensure that the appropriate user profile is loaded. The teacher/parent might be authorized to help the child with the authentication (for example, by knowing the login name and password) so as the child can take part in the program, even when he/she has forgotten the authorization details. When a child is using the system, the loaded profile may be also used for producing a feedback report, which will assist the teacher/parent to guide the child.

During the development of the serious games, children with/without dyslexia will be asked to play games and their actions will be recorded. The collected data, together with other information related to the child's profile (dyslexia type, reading error sensitivity, etc), will be used to develop user models that will be utilized in the serious game engine development. The collected data will be anonymized, by the educational partners collecting them (DYSACT, EPIRUS) and will be transmitted to the partner responsible for serious game development (UoM).

4.3. Evaluation of ILearnRW

The main goal of the ILearnRW project is to improve the reading / spelling skills of its users. In the evaluation phase of the project, the ILearnRW system will be tested in two test-beds (UK and Greece) with children having dyslexia and/or dysorthographia. The test-bed specification will determine the details of the testing (number of participants, testing period, testing scenarios, etc) . The testing period is likely to last at least 6 months and during it the ILearnRW system will maintain the profiles of several children participating in the trial. These profiles contain information regarding the dyslexia status of the child and, thus, can be considered to be "sensitive data". In addition to data related to user profiles, the children and their tutors will be asked to evaluate several aspects of the software with respect to the software through the use of questionnaires. The tutors/speech therapy experts will be also asked to evaluate the children's learning progress during the trial period.

[10] A final decision will be taken during the design of the ILearnRW's system architecture.

When extracted for processing, the personal details of the children will be consistently substituted be a "code number" that will guarantee anonymity. Correlation to real persons will only be possible if one combines the login details of the ILearnRW software and the access privileged of these researchers. Even in this way, the correlation of sensitive with real names may only be possible till the end of the project. Afterwards, the initial details of the real persons will be deleted and data belonging to the same person will be identified based on the common "code number" they share.

The profiles and statistics collected during evaluation as well as all data collected during the development/ training of the ILearnRW software will be "anonymized". In the scope of the ILearnRW system development, the data need not to be stored, only temporarily recorded, since they are used for the development/training of the software. However, as it holds with data collected during the evaluation, in order to be able later on to prove, in scientific terms, the validity of the methodology used, keeping these anonymous profiles/data will be helpful, for a certain time period (e.g. five years). In order to keep these data consent will be sought from the parents of the children involved.

5. Information Security

As described in the previous section, personal data, which are anonymous will be collected during the phase of software development and training. Sensitive data will be also collected during the phase of evaluation of the ILearnRW software. The sensitive data will be stored in a central "project server", or a server maintained by the corresponding project partner, in the form of user profiles (and data used to construct them). These profiles will be password and/or IP address protected. Thus, no unauthorized person in the scope of the project will have access to these data.

5.1. Data Security during Research

Data will be collected and stored at different research sites, or at the project's server, only visible to the research site network. These servers will be firewall protected. Logs of all the servers' activity can be kept continuously and backups of the logs will be done periodically, so that actions performed upon the data can be monitored and responsibilities attributed.
Only anonymous data will be available for processing. Moreover, authentication will be required by researchers to access stored data on the research sites. If an exchange of traceable personal data among the different research sites is required, for example, due to the need of some researchers of data collected in another country, secure transition mechanisms will be employed (for example, secure ftp, or explicit encryption/ decryption).

5.2. Data Security in the Final System

The data security issues in the final system are those of a typical client / server application and concern the unauthorized access of the server and the transmission of application data. Both of these issues will be addressed by applying standard available software solutions (use of encryption / decryption techniques, allowing access only to specific client server applications, firewalls, etc). The exact mechanisms to be employed will be decided during implementation time and will depend on design decisions concerning the architecture of the software system.

5.3. ILearnRW Consortium Policy on Ethical Issues (data collection, storage and processing)

In order to ensure the observance of the above rules, responsibilities should be explicitly distributed among partners.

1. Each partner is responsible for storing the data it collects at a local server behind a firewall. The partner should make the data available to other partners, who need to process them, or conduct a statistical analysis, by a secure mechanism (for example, secure ftp, password protected etc).
2. Each partner responsible for data collection is also responsible for obtaining the permission to do so (from the relevant local authorities, if required).

3. Each partner responsible for data processing is also responsible for obtaining the permission to do so (from the relevant local authorities, if required). Partners who need and receive data from other partners, should use them only for the purposes of the project and should comply with all commitments (stated in consent and notification forms) made by the partner responsible for data collection. They may be asked to sign (if required by the national authorities) a document indicating their agreement.

4. For the evaluation phase of the project, user profiles and other sensitive data will be collected stored and analyzed. The partner responsible for processing of sensitive data will be also responsible for obtaining the necessary permission to store "sensitive data".

5.4. Consent and Notification Forms

During the project execution, a consent form should be signed by

- Parents/guardians of a child participating in the training of the software. They should be informed of the purpose and the methodology used by the project. They should also be informed of their rights, concerning the data related to the child. They should give consent prior to data collection.

- /guardians of a child participating in the use and evaluation of the software. They Parents should be informed of the purpose and the methodology used during the project's evaluation. They should also be informed of their rights, concerning the data related to the child and the child's participation. They should give consent prior to data collection.

In addition, tutors and researchers involved should be informed of their responsibilities, when handling personal data of children. If required by the national authorities, they may sign a notification form, indicating that they are aware of these responsibilities. Thus, a notification form is ready to be signed by

- Teachers interacting with the children contributing in data collection: They should be informed of the fact that they are involved with sensitive data of children and sign that they are aware of the responsibilities arising from this interaction.

- Researchers involved in the ILearnRW project who have access to personal and/or sensitive data of the children: They should be informed of the fact that these data are confidential and can be used only for scientific research. They should sign that the conclusions or the output of statistical analysis of the data can be announced/published, but the data concerning specific persons will in no way be notified to any third parties. The same form may be signed (if needed, alternatively to obtaining a separate permission from local authorities) by a member of another ILearnRW partner, who needs to have access to the data collected.

Templates of the above forms (in English and Greek) are given at the Appendix. During the course of the ILearnRW project these forms may be updates/modified, according to the arising needs of the project.

APPENDIX

Consent and Notification Forms

The ILearnRW project is financed by the Seventh Framework Programme
Information and Communication Technologies
ICT for Learning and Cultural Resources (Technology Enhanced Learning)

CONSENT FORM
CONCERNING THE CHILDREN THAT WILL PARTICIPATE IN THE DEVELOPMENT/EVALUATION OF THE ILEARNRW SOFTWARE

On _____<date>_____, in _____<place>_____the following signing persons _____<name>_____ , who will be referred to as the GUARDIAN, as the legal representative of the under-aged _____<name>_____, who will be referred to as the CHILD, and _____<name>_____, as a representative of the ILearnRW consortium, who will be referred to as the REPRESENTATIVE are giving consent to the following:

Statement of Purpose

The **aim of the ILearnRW project** is to *develop a next generation learning software* which uses a computer to facilitate the learning process for children with dyslexia and/or dysorthographia.

Towards that aim, the Scientific and Technological objectives of the project are:

1) *The development of an Integrated Intelligent Learning Environment for Reading and Writing* (the ILearnRW system) which:
   - supports user profiling
   - incorporates learning/teaching strategies
   - supports the classification of learning material based on user profile
   - supports personalized content presentation
   - supports engaging learning activities
   - supports the evaluation of learning
   - incorporates an on-line resource data bank.
2) *The evaluation of the ILearnRW system* in terms of its overall success in promoting the learning process of reading and writing through extensive field-testing in different language settings (UK and Greece).

Your child's involvement

In order to develop and/or evaluate the ILearnRW software, data from children are needed. The data may concern the child's opinion/preference with respect to particular aspects of the system or their profile and actions while using the system either during its development or its evaluation. These data may be combined with information specific to the child's dyslexia status. Not all children that will participate in the stage of software will have necessarily dyslexia/dysorthographia

Risks assessment

In the scope of the ILearnRW project, when the personal details of the children are extracted for processing they will be consistently substituted be a "code number" that will guarantee anonymity. Correlation to real persons will only be possible if one combines the code number and information available to only a limited number of privileged researchers of the ILearnRW project team. Even in this way, the correlation of sensitive data with real names may only be possible till the end of the project. Afterwards, the details of the real persons will be deleted and data belonging to the same person will be identified only based on the common "code number" they share. These anonymous data will be stored for a period of at most five years in order to be able to prove, in scientific terms, the validity of the research findings and of the methodology used.

The data will be kept in a secure server. They will be accessed only by researchers, directly involved in the ILearnRW project, who are responsible for the development of the ILearnRW learning system. The researchers will be a priori informed about the responsibilities and risks of accessing such personal data.

Your rights

- You may at any time ask for access to the personal/sensitive data concerning the CHILD, provided that they can be located.
- You may at any time ask for erasure, blocking or rectification of the data concerning the CHILD, provided that they can be located.
- You may at any time ask to be further informed of all relevant details relating to the data processing and the rights granted to you.
- The participation is voluntary and you may withdraw from the research at any time once participation has begun.

This consent form is signed in two copies, one for the GUARDIAN and one for the ILearnRW consortium representative.

I have been informed and I can understand all of the above terms and conditions.
I am giving consent to all of them.

For the ILearnRW consortium

The GUARDIAN

The REPRESENTATIVE

Το πρόγραμμα ILearnRW χρηματοδοτείται από το 7ο Πρόγραμμα Πλαίσιο της Ευρωπαϊκής Ένωσης,
Information and Communication Technologies
ICT for Learning and Cultural Resources (Technology Enhanced Learning)

ΈΝΤΥΠΟ ΣΥΓΚΑΤΑΘΕΣΗΣ ΓΙΑ ΤΑ ΠΑΙΔΙΑ ΠΟΥ ΣΥΜΜΕΤΕΧΟΥΝ ΣΤΗΝ ΑΝΑΠΤΥΞΗ/ΑΞΙΟΛΟΓΙΣΗ ΤΟΥ ΛΟΓΙΣΜΙΚΟΥ ILEARNRW

Σήμερα, την _____ <ημερομηνία>
_____ <τόπος>
οι κάτωθι υπογεγραμμένοι:
ο/η _____ , ο οποίος στη συνέχεια θα αναφέρεται ως ΚΗΔΕΜΟΝΑΣ και είναι ο νόμιμος εκπρόσωπος του ανήλικου _____, ο οποίος στη συνέχεια θα αναφέρεται ως ΠΑΙΔΙ και ο/η _____ , ως εκπρόσωπος του ILearnRW Consortium, ο οποίος στη συνέχεια θα αναφέρεται ως ΥΠΕΥΘΥΝΟΣ συναινούν στα εξής:

Σκοπός του προγράμματος ILearnRW

Σκοπός του προγράμματος ILearnRW είναι η ανάπτυξη μαθησιακού εκπαιδευτικού λογισμικού νέας γενιάς το οποίο χρησιμοποιεί τον υπολογιστή για να διευκολύνει τη διαδικασία μάθησης για τα παιδιά με δυσλεξία και /ή δυσορθογραφία.

Για την επίτευξη του σκοπού αυτού, οι τεχνολογικού και επιστημονικοί στόχοι του προγράμματος ILearnRW είναι:

1. Η ανάπτυξη ενός *Έξυπνου Περιβάλλοντος μάθησης για Ανάγνωση και Γραφή* (Integrated Intelligent Learning Environment for Reading and Writing; ILearnRW) το οποίο:
   - Υποστηρίζει εξατομικευμένο προφίλ για κάθε παιδί,
   - Ενσωματώνει στρατηγικές διδασκαλίας/μάθησης
   - Υποστηρίζει την εξατομικευμένη (με βάση το προφίλ) παρουσίαση κειμένου
   - Υποστηρίζει μαθησιακές δραστηριότητες που έλκουν/δραστηριοποιούν το παιδί
   - Υποστηρίζει την αξιολόγηση της διαδικασίας μάθησης
   - Ενσωματώνει την πρόσβαση σε άμεσα διαθέσιμο εκπαιδευτικό υλικό
2. Η αξιολόγηση του συστήματος ILearnRW ως προς το κατά πόσο προάγει την διαδικασία μάθησης της ανάγνωσης και της γραφής μέσω εκτεταμένης δοκιμαστικής χρήσης σε γλωσσικά-διαφορετικά περιβάλλοντα (Αγγλία και Ελλάδα)

Η συμμετοχή του παιδιού σας

Προκειμένου να αναπτυχθεί και να αξιολογηθεί επιστημονικά η χρησιμότητα του λογισμικού ILearnRW, απαιτούνται δεδομένα από παιδιά. Τα δεδομένα αυτά μπορεί να αφορούν τη γνώμη/ προτίμηση του παιδιού σε σχέση με συγκεκριμένες πτυχές του συστήματος ILearnRW ή το προφίλ του παιδιού και τις δράσεις/κινήσεις του κατά τη χρήση του συστήματος ILearnRW. Τα δεδομένα αυτά μπορεί να συλλεχθούν είτε κατά τη διάρκεια της ανάπτυξής του συστήματος ILearnRW ή κατά τη φάση αξιολόγησης του και μπορεί να συνδυάζονται με τις ειδικές πληροφορίες που αφορούν την

δυσλεξία του παιδιού. Σημειώνεται ότι όλα τα παιδιά που θα συμμετάσχουν στην ανάπτυξη/ αξιολόγηση του λογισμικού δεν θα έχουν απαραίτητα δυσλεξία / δυσορθογραφία.

Εκτίμηση κινδύνων

Στο πλαίσιο του προγράμματος ILearnRW, όταν τα δεδομένα ενός παιδιού προωθούνται προς επεξεργασία, τα στοιχεία αναγνώρισης του (δηλ. όνομα, επίθετο) θα αντικαθιστούνται με έναν *κωδικό αριθμό* μέσω του οποίου θα εξασφαλίζεται η ανωνυμία. Η συσχέτιση των δεδομένων με ένα παιδί θα είναι μόνο δυνατή εάν κάποιος συσχετίσει τον κωδικό αριθμό με πληροφορίες διαθέσιμες μόνο σε ένα περιορισμένο αριθμό ερευνητών του προγράμματος ILearnRW. Η δυνατότητα αυτή θα σταματήσει να υφίσταται στο τέλος του προγράμματος. Τότε, τα στοιχεία αναγνώρισης των παιδιών θα διαγραφούν και πρόσβαση σε δεδομένα που ανήκουν στο κάποιο παιδί θα είναι δυνατή μόνο μέσω του κωδικού αριθμού. Τα *ανώνυμα* αυτά δεδομένα θα διατηρηθούν για διάστημα το πολύ πέντε ετών ώστε να είμαστε, εάν χρειαστεί, σε θέση να αποδείξουμε με επιστημονικούς όρους την εγκυρότητα της μεθοδολογίας που ακολουθήθηκε

Τα δεδομένα θα φυλάγονται σε ασφαλή εξυπηρετητή δεδομένων. Σε αυτά θα έχουν πρόσβαση μόνο ερευνητές, οι οποίοι εμπλέκονται άμεσα στο πρόγραμμα ILearnRW και οι οποίοι είναι υπεύθυνοι για τις εργασίες επεξεργασίας δεδομένων του προγράμματος. Θα είναι εκ των προτέρων ενημερωμένοι για τις ευθύνες που ενέχει η προσπέλαση προσωπικών δεδομένων.

Τα δικαιώματά σας

- Μπορείτε ανά πάσα στιγμή να ζητήσετε πρόσβαση στα προσωπικά / ευαίσθητα δεδομένα που αφορούν το ΠΑΙΔΙ, υπό την προϋπόθεση ότι αυτά μπορούν να εντοπιστούν από τους υπευθύνους.
- Μπορείτε ανά πάσα στιγμή να ζητήσετε να σβηστούν, ή να διορθωθούν τα δεδομένα που αφορούν το ΠΑΙΔΙ, υπό την προϋπόθεση ότι αυτά μπορούν να εντοπιστούν από τους υπευθύνους.
- Μπορείτε ανά πάσα στιγμή να ζητήσετε να ενημερωθείτε με περισσότερες λεπτομέρειες για όλα τα θέματα που σχετίζονται με την επεξεργασία δεδομένων και τα δικαιώματά σας.
- Η συμμετοχή είναι προαιρετική και μπορείτε ανά πάσα στιγμή να αποσυρθείτε από το ερευνητικό πρόγραμμα, ακόμη και αν η συμμετοχή σας έχει ήδη ξεκινήσει.

Το έντυπο αυτό υπογράφεται σε δύο αντίγραφα, ένα για τον ΚΗΔΕΜΟΝΑ και ένα για τον ΥΠΕΥΘΥΝΟ.

Έχω λάβει γνώση και κατανοώ όλους τους παραπάνω όρους και προϋποθέσεις.
Συναινώ σε όλα από τα παραπάνω.

Εκ μέρους της ομάδας ILearnRW

Ο ΚΗΔΕΜΟΝΑΣ

Ο ΥΠΕΥΘΥΝΟΣ

The ILearnRW project is financed by the Seventh Framework Programme
Information and Communication Technologies
ICT for Learning and Cultural Resources (Technology Enhanced Learning)

NOTIFICATION FORM
CONCERNING A TEACHER PARTICIPATING IN THE ILEARNRW PROJECT

The **aim of the ILearnRW project** is to *develop a next generation learning software* which uses a computer to facilitate the learning process for children with dyslexia and/or dysorthographia.

Towards that aim, the Scientific and Technological objectives of the project are:

1) *The development of an Integrated Intelligent Learning Environment for Reading and Writing* (the ILearnRW system) which:
   - supports user profiling
   - incorporates learning/teaching strategies
   - supports the classification of learning material based on user profile
   - supports personalized content presentation
   - supports engaging learning activities
   - supports the evaluation of learning
   - incorporates an on-line resource data bank.
2) *The evaluation of the ILearnRW system* in terms of its overall success in promoting the learning process of reading and writing through extensive field-testing in different language settings (UK and Greece).

The knowledge of the personal details of children participating in the ILearnRW project and their corresponding data (including code numbers, login names and passwords for the ILearnRW software) is confidential. The teacher may announce his/her personal conclusions from the use of the ILearnRW experience, but (s)he cannot refer to specific persons.

Το πρόγραμμα ILearnRW χρηματοδοτείται από το 7ο Πρόγραμμα Πλαίσιο της Ευρωπαϊκής Ένωσης,
Information and Communication Technologies
ICT for Learning and Cultural Resources (Technology Enhanced Learning)

ΈΝΤΥΠΟ ΕΝΗΜΕΡΩΣΗΣ ΓΙΑ ΤΟΥΣ ΕΚΠΑΙΔΕΥΤΙΚΟΥΣ ΠΟΥ ΣΥΜΜΕΤΕΧΟΥΝ ΣΤΟ ΠΡΟΓΡΑΜΜΑ ILEARNRW

Σκοπός του προγράμματος ILearnRW είναι η ανάπτυξη μαθησιακού εκπαιδευτικού λογισμικού νέας γενιάς το οποίο χρησιμοποιεί τον υπολογιστή για να διευκολύνει τη διαδικασία μάθησης για τα παιδιά με δυσλεξία και /ή δυσορθογραφία.

Για την επίτευξη του σκοπού αυτού, οι τεχνολογικού και επιστημονικοί στόχοι του προγράμματος ILearnRW είναι:

3. Η ανάπτυξη ενός *Έξυπνου Περιβάλλοντος μάθησης για Ανάγνωση και Γραφή* (Integrated Intelligent Learning Environment for Reading and Writing; ILearnRW) το οποίο:
   - Υποστηρίζει εξατομικευμένο προφίλ για κάθε παιδί,
   - Ενσωματώνει στρατηγικές διδασκαλίας/μάθησης
   - Υποστηρίζει την εξατομικευμένη (με βάση το προφίλ) παρουσίαση κειμένου
   - Υποστηρίζει μαθησιακές δραστηριότητες που έλκουν/δραστηριοποιούν το παιδί
   - Υποστηρίζει την αξιολόγηση της διαδικασίας μάθησης
   - Ενσωματώνει την πρόσβαση σε άμεσα διαθέσιμο εκπαιδευτικό υλικό
4. Η αξιολόγηση του συστήματος ILearnRW ως προς το κατά πόσο προάγει την διαδικασία μάθησης της ανάγνωσης και της γραφής μέσω εκτεταμένης δοκιμαστικής χρήσης σε γλωσσικά-διαφορετικά περιβάλλοντα (Αγγλία και Ελλάδα)

Η γνώση των στοιχείων των παιδιών που συμμετέχουν στο ερευνητικό πρόγραμμα ILearnRW και των αντιστοίχων προσωπικών δεδομένων, συμπεριλαμβανομένων των κωδικών αριθμών, κωδικών ονομάτων (login names) και κωδικών πρόσβασης (passwords) είναι εμπιστευτική. Ο εκπαιδευτικός μπορεί να δημοσιεύσει/ανακοινώσει με στατιστικά στοιχεία τα συμπεράσματά του σχετικά με τη διαδικασία και τις μεθόδους που ακολουθούνται στο πρόγραμμα ILearnRW. Δεν μπορεί, όμως, σε καμία περίπτωση να αναφερθεί σε συγκεκριμένα άτομα.

The ILearnRW project is financed by the Seventh Framework Programme
Information and Communication Technologies
ICT for Learning and Cultural Resources (Technology Enhanced Learning)

NOTIFICATION FORM
CONCERNING A TEACHER PARTICIPATING IN THE ILEARNRW PROJECT

On _____<date>_____ , in _____<place>_____, the following signing person _____<name>_____ , who will be referred to as the RESEARCHER has been informed of the following:

The RESEARCHER involved in the ILearnRW project may have access to personal and / or sensitive data of children. (S)he knows that these data are confidential and can be used only for scientific research. The conclusions or the output of statistical analysis of the data can be announced / published. The data concerning specific persons cannot be notified to any third parties.

I have been informed and I can understand the above terms and conditions.

The RESEARCHER

Το πρόγραμμα ILearnRW χρηματοδοτείται από το 7ο Πρόγραμμα Πλαίσιο της Ευρωπαϊκής Ένωσης,
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ΈΝΤΥΠΟ ΕΝΗΜΕΡΩΣΗΣ
ΓΙΑ ΤΟΥΣ ΕΡΕΥΝΗΤΕΣ ΠΟΥ ΣΥΜΜΕΤΕΧΟΥΝ ΣΤΟ ΠΡΟΓΡΑΜΜΑ ILEARNRW

Σήμερα, την _____ <ημερομηνία>
_____ <τόπος>
ο/η κάτωθι υπογεγραμμένος/η _____ , ο/η οποίος/α στη συνέχεια θα αναφέρεται ως ΕΡΕΥΝΗΤΗΣ ενημερώθηκε για τα εξής:

Ο ΕΡΕΥΝΗΤΗΣ με τη συμμετοχή του του στο πρόγραμμα ILearnRW μπορεί να έχει πρόσβαση σε προσωπικά ή / και ευαίσθητα δεδομένα που αφορούν παιδιά. Γνωρίζει ότι τα δεδομένα αυτά είναι εμπιστευτικά και μπορούν να χρησιμοποιηθούν μόνο για επιστημονική έρευνα. Τα συμπεράσματά του ή τα αποτελέσματα στατιστικής ανάλυσης των δεδομένων μπορούν να δημοσιευθούν ή να ανακοινωθούν. Με κανέναν τρόπο δεν μπορούν να γνωστοποιηθούν σε άλλα άτομα δεδομένα που αφορούν μεμονωμένα/συγκεκριμένα άτομα, ανεξάρτητα από το εάν μπορεί από τα δεδομένα αυτά να εξαχθεί η ταυτότητά τους ή όχι.

Έχω λάβει γνώση και κατανοώ τους παραπάνω όρους και προϋποθέσεις.

Ο ΕΡΕΥΝΗΤΗΣ