DICE

Digital Inclusion Champions in Europe

ETHICAL PROCEDURES MANUAL

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For further information related to the DICE project please visit:

the project website (www.dice-project.eu);

Facebook page (facebook.com/digichampion);

Twitter page (twitter.com/dice_project).

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Acronyms & Vocabulary

ACRONYM / TERM	EXPLANATION
Study	Any questionnaire (online or paper, etc.), interview, focus group, experimental or quasi-experimental investigation, and any collection of data from a participant (e.g. monitoring of computer behaviour for collection of strategies or user modelling data)

1   Introduction

This document will guide the ethics of all the work within the I2Web Project that deals with human participants. Human participants include those from all stakeholder groups:

- Digital skills students with disabilities;

- Other people with disabilities;

- Digital skills trainers and other VET Centre staff;

- Mainstream educators;

- Employers.

The DICE consortium will ensure that these ethical guidelines are adhered to in all activities of the project, including the following:

- Stakeholder recruitment;

- Stakeholder requirements gathering;

- Community website user testing;

- Developing peer support relationships;

- Developing Champions;

- DICE Community involvement;

- Community experience evaluation;

- Dissemination.

Information will be gathered from people within these groups via questionnaires, surveys, focus groups, interviews, website sign-up and login forms, website content input forms and observation of individuals accessing the DICE Community portal website using a variety of devices. Information about individuals may also be disseminated by the project. Particular attention will be paid to participants with disabilities, who are more vulnerable than other groups and for whom the personal information collected may be more sensitive.

These ethical guidelines are based largely on the following sources:

- British Psychological Society Code of Conduct: Ethical Principles for Conducting Research with Human Participants (http://www.bps.org.uk/the-society/code-of-conduct/support-for-researchers_home.cfm)

- American Psychological Association: Ethical Principles of Psychologists and Code of Conduct (http://www.apa.org/ethics/code/index.aspx)

The ethical principles that will be adhered to are divided into the following areas:

- Communication

- Recruitment

- Briefing

- Informed Consent

- Welfare and dignity of participants

- Debriefing

- Withdrawal of consent

- Confidentiality, anonymity and data protection

- Development of further ethical procedures

No other areas of ethical concern have yet been identified in the DICE Project. If additional issues arise, this document will be amended to include them.

NCBI, as project co-ordinator, is responsible for the overall management of ethical issues within the project. Each consortium partner is responsible for ethical issues management of the activities they carry out. At a national level, NCBI is responsible for ethical issues management in Ireland, PhoenixKM in Belgium, Interprojects in Bulgaria and FIRR in Poland.

These ethical guidelines are not intended to replace any ethical procedures already in operation within partner organisations or countries and which partners are required to follow. In case of any conflict between existing ethical procedures and the guidelines in this document, partners should inform the DICE project co-ordinator (NCBI) who will work with them to resolve the conflicts in a manner which offers best protection to the participants, the partner and the project.

2   Procedures

2.1   Communication

All communication or information given to participant or potential participants must be presented to them in a suitable format that they are able to perceive and understand. For example, participants without sight may require information in Braille, audio or an accessible digital format that they have the means to access. Participants who are deaf may require written information or sign language interpretation. All written or spoken information should be in simple language free from unnecessary jargon. This applies during recruitment and all subsequent stages of the project.

The stakeholder recruitment and requirements gathering plan will include guidance on how to communicate effectively with people with different disabilities.

2.2   Recruitment

During the recruitment of potential participants to take part in the project or its activities, participants must be given sufficient accurate information to enable them to make an informed decision about whether they wish to take part.

For example, when recruiting members for the National Steering Group, a fact sheet about the project and the purpose and activities of the steering group might be included along with letters of invitation. When recruiting members of the DICE Community website for usability and accessibility evaluation, recruitment request should outline the nature and purpose of the user tests. When approaching members of a training class without prior recruitment for informal feedback about their experiences with the DICE Community, it may be sufficient for the interviewer to read a short prepared statement before asking the participant to agree to the interview.

Potential participants should not have undue psychological pressure placed on them to be part of the project or any activity. For example, it should not be suggested that it is a requirement of a course or that it would be beneficial for a course. Particular attention should be given if the person managing or administering the activity is in a position of authority or influence over participants who may be their students, employees or clients. This relationship should not be allowed to pressurize the participants.

Participants may be offered reimbursement, (in money or in kind) but only to a level commensurate with the effort involved in their participation. They should not be offered reimbursement that may cause them to act against their better judgement or risk harm beyond that which they risk without payment in their normal lifestyle

2.3   Briefing

Prior to taking part in any study administered by the project, participants should receive a briefing giving the following information:

- What they will be asked to do;

- How long will it take;

- Who will be conducting the study and who will be present;

- That they have a right to withdraw at any time without any negative consequences (including the withholding of any agreed reimbursement), and how to do so;

- Any parts of the study that are optional;

- A reasonable estimation of whether it will be difficult, stressful, boring, etc.;

- Whether they will be audio or video recorded and what exactly the recording will include (for example, their face and actions);

- Who will have access to the data that is collected, where and how long it will be stored, with appropriate information about anonymity and confidentiality;

- How the results will be disseminated and to who.

This information may be presented on an Informed Consent Form (see 2.4 below), in which case it may be read by the person administering the study or given to the participant to read, according to whatever is most appropriate for communicating the information.

Participants should be given the opportunity to ask any questions they wish during the briefing.

2.4   Informed Consent

Prior to taking part in any study administered by the project, participants should be informed of all aspects of the study that might reasonably be expected to influence their willingness to participate. They should be given the opportunity to ask any questions they wish. The agreement to take part should normally involve the participant completing and signing an Informed Consent Form and providing them with a copy.

The contents of the Informed Consent Form will vary according to the nature of the study but will normally include the information given in the briefing (see 2.3 above).

In some cases it may be difficult or impossible or inappropriate for the person to sign a consent form and alternative means of giving consent may be used. For example, a visually impaired participant may not wish to sign a printed form if they cannot see what is written on it. An alternative in this case would be to allow the person to read an accessible digital version of the form (for example on a digital device using text to

speech or magnification), print the form themselves and then sign it. Another alternative, suitable for both visually impaired participants and those with severe physical disabilities, would be to video record them making a spoken consent statement.

2.5   Welfare and dignity of participants

Investigators have a primary responsibility to protect participants from physical and mental harm during the investigation. Normally, the risk of harm must be no greater than in ordinary life, i.e. participants should not be exposed to risks greater than or additional to those encountered in their normal lifestyles.

Where project activities might result in undesirable consequences for participants, the administrator of the activity should detect and remove or correct these consequences. Where activities may involve behaviour or experiences that participants may regard as personal and private, participants should be protected from stress by all appropriate measures, including the assurance that answers to personal questions need not be given. There should be no concealment or deception when seeking information that might encroach on privacy.

During project activities, participants should be treated with respect and common sense. They should not be asked to undertake activities for unreasonable periods without comfort and refreshment breaks, in conditions that are uncomfortable etc. They should feel that they can ask for breaks, refreshments, etc. as reasonable.

When undertaking tasks that involve accessing digital systems and content, participants should be given access to appropriate hardware, software and support so that they can access these in an appropriate and comfortable manner.

2.6   Debriefing

Following participation in any study administered by the project, participants should be thanked for their participation and debriefed by giving them the following information:

- A final verbal description of the nature of the study;
- That their participation was useful and worthwhile for the success of the project;
- How the data will be analysed;
- That they have a right to withdraw retrospectively any consent given, and to require that their own data, including recordings, be destroyed.

Participants should be given a final opportunity to ask any questions they wish during the debriefing.

Participants should be asked about their experience of taking part in the study, in order to monitor any unforeseen negative effects or misconceptions. They should be informed of how to contact project staff within a reasonable time period following participation should stress, potential harm, or related questions or concern arise.

2.7   Withdrawal of consent

In the light of experience of the investigation, or as a result of debriefing, the participant has the right to withdraw retrospectively any consent given, and to require that their own data, including recordings, be destroyed.

2.8   Confidentiality, anonymity and data protection

Care should be taken to ensure the confidentiality and anonymity of participants' data. In addition to the guidelines in this document, all data protection legislation and regulations applicable in the EU or partner countries must be adhered to.

Information obtained about a participant during a project activity should be treated as confidential unless otherwise agreed in advance. Participants have a right to expect that information they provide will be treated confidentially and, if published, will not be identifiable as theirs unless this is appropriate and that they have given prior consent.

When information from studies is stored in digital files, participants should only be referred to by a code that cannot identify them. For example, codes including the participants' initials should be avoided. One member of staff in a partner organisation should retain the mapping from codes to participant names, but this information should not be stored on a computer and should be kept in a secure place. Participants who are registered on the Community website will have their details stored on a server controlled by the consortium. Data that is required to identify a participant (e.g. for logging in purposes) for the normal operation of the website can be stored without requiring such offline mapping.

All digital files should be stored only on secure machines. Particular care should be taken on security issues if files are transferred between partners for analysis. This should be undertaken using secure means.

Audio and video files should not be shown beyond the immediate research team without the explicit permission of the participants. For example, if an excerpt from a videoed session is to be used at a public presentation such as a conference, explicit permission should be obtained from the participant(s) involved.

When data are reported in project deliverables or in public documents, attention must be paid to the anonymity of data. Data should mainly be reported in an aggregate manner, so that information from individual participants cannot be identified. If individual information is included, for example, comments from individual participants, it should be reported in ways that does not identify or embarrass the individual.

2.9   Development of further ethical procedures

Certain project activities will require the development of ethical procedures and guidelines to be followed by DICE Community members during Community participation, peer-support relationships, Championing, etc. These should be based on the guidelines contained in this document wherever possible and appropriate.