DELIVERABLE

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D 2.2 Privacy Framework and Ethical Checklist Revision: 1.1

Authors:

Gina Sands (Coventry University Enterprises Ltd – Health Design & Technology Institute)

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P	Public	✓
C	Confidential, only for members of the consortium and the Commission Services	

Revision History

Revision	Date	Author	Organisation	Description
1	26/06/12	Gina Sands	HDTI	
1.1	09/07/12	Gina Sands	HDTI	Amends from OU to match with D2.1

Statement of originality:

This deliverable contains original unpublished work except where clearly indicated otherwise. Acknowledgement of previously published material and of the work of others has been made through appropriate citation, quotation or both.

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Deliverable D 2.2 – Privacy Framework and Ethical Checklist

Introduction

This document provides the Privacy framework and Ethical checklist for the DISCOVER project. It includes a description of the Privacy Impact Assessment (PIA) process with reference to the UK Information Commissioner's Office Handbook. In addition to the guidance given here, partners should refer to the User Methodology Handbook for guidance, particularly relating to confidentiality and privacy; consent, autonomy and choice; justice/fairness; inclusion; security; and dignity, before completing the PIA and ethical checklist. There are also two appendices with simplified and practical guidance for individual tasks. Appendix A contains a template that has been developed for the DISCOVER project to assist partners in conducting a PIA. This template should be completed for each task which may involve privacy issues using the guidance set out in Section 2. Appendix B contains an ethical checklist which all activities within the DISCOVER project should adhere to as a minimum. This should be considered alongside the ethics Section of the User Methodology Handbook.

Privacy Impact Assessment

Projects that involve collecting personal information will give rise to privacy concerns. A Privacy Impact Assessment (PIA) is a process that is undertaken to help organisations to anticipate the privacy impacts of projects and then manage them/develop solutions. The PIA process is best started at the beginning of a project so that any privacy concerns can be addressed in the changing design of the project. It is much more difficult to address privacy concerns when the project is fully developed. It is important to acknowledge that privacy issues are likely to arise in this type of project and if managed well should not be a concern.

The following section of this report offers a PIA process based on the information given in the PIA handbook published by the UK Information Commissioner's Office (ICO, accessed May 2012). In the project proposal a small-scale PIA was deemed appropriate for DISCOVER. This takes elements of the full-scale PIA but has a more informal and limited approach. The full PIA process is explained below and should be taken into consideration when each partner conducts their own PIA. However, a template has been developed for the DISCOVER project (Appendix A) which should simplify the process and also act as the documentation required for steps 2, 3 and 4 (detailed below).

PIA Process

The first step is the PIA screening process which assists in making the decision of whether a PIA is needed and, if so, at which level. The Information Commissioner's Office (ICO, 2012) states that a full-scale PIA "conducts a more in-depth internal assessment of privacy risks and liabilities, analyses privacy risks, consults widely with stakeholder on privacy concerns and brings forward solutions to accept, mitigate or avoid them". A small-scale PIA is similar but less formalised and has less

exhaustive information gathering and analysis than a full-scale assessment. As previously mentioned, a small-scale PIA was deemed most appropriate for DISCOVER in the project proposal.

Figure 1 gives an overview of the PIA process, which includes preparation / preliminary work, external consultation, information gathering and the documentation and review phases. Each of these phases are explained below. The template in Appendix B also gives further guidance on how to conduct the PIA and is referenced throughout the next sections.
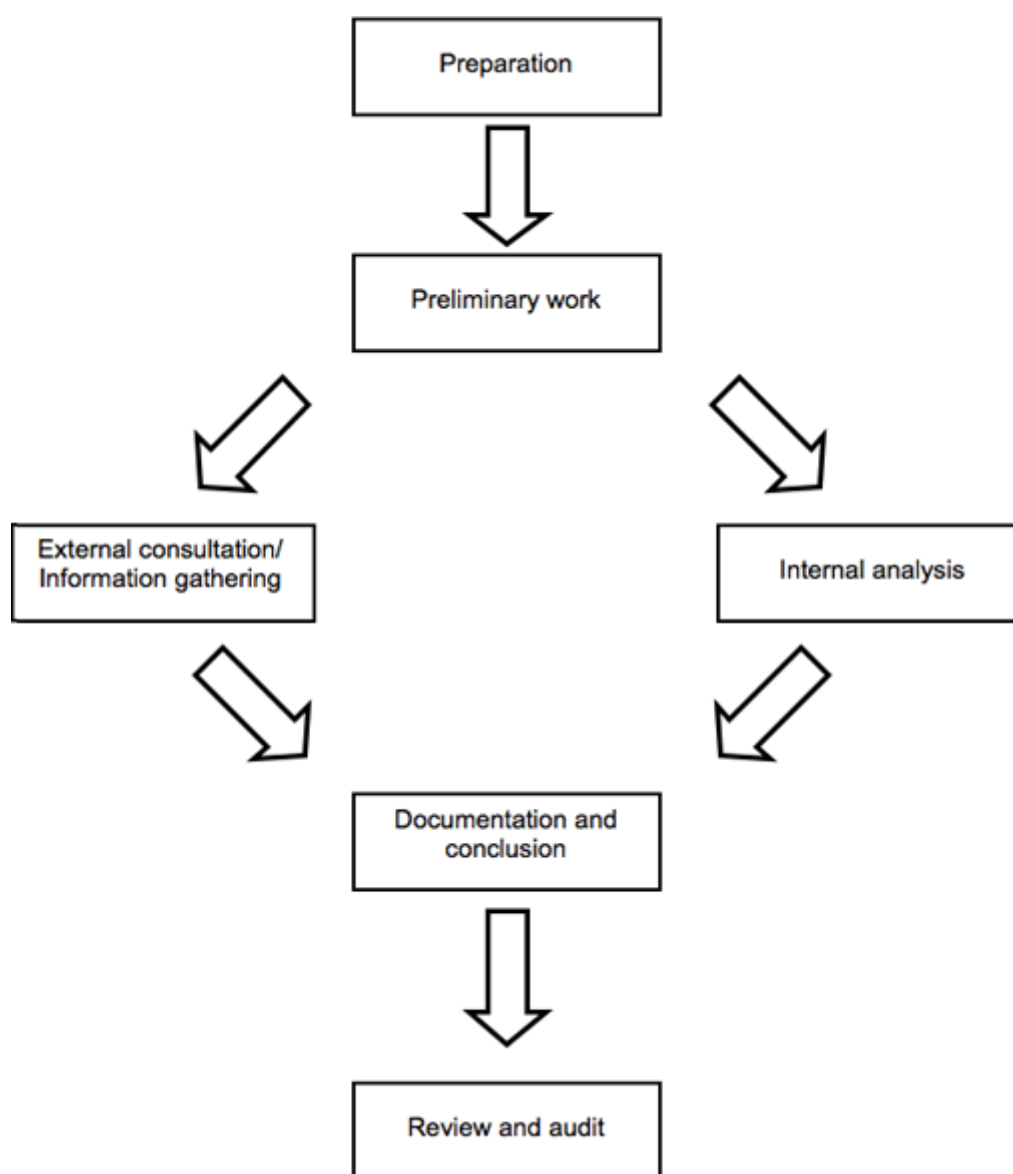

Figure 1 – PIA Process Map (ICO, 2012)

Preparation and Preliminary Phases

The purpose of the preparation and preliminary phases is to make arrangements and establish a firm basis for the PIA to be conducted effectively and efficiently. This would usually include: a

project plan/outline; identifying stakeholders; preliminary assessment of privacy concerns; and establishing a PIA Consultative Group/main contact. This document serves as the initiation of these phases by setting out the process of the PIA and suggesting some relevant privacy issues. Each partner organisation shall conduct their own PIA for each privacy related task/activity using the template provided in Appendix B, if multiple partners are working on the same task then only one PIA template needs to be completed. Coventry University (Health Design &Technology Institute, HDTI) will act as the main contact for the PIA process, consulting and involving partners as appropriate. Coventry University (HDTI) will also take responsibility for collating completed PIA templates into a PIA report which will be adapted as the DISCOVER project grows.

Action points

The contribution for each partner to these stages will be items 1 & 2 of the PIA template.

- Provide a brief outline of the activity that can be easily understood by stakeholders and partners who are not directly involved in the activity.
- Identify and list the key stakeholders of the project with the intention of consulting with them in the next stage. It may also be wise to initiate contact by sending stakeholders the activity outline prepared in the previous point so they are familiar with the activity before consultation begins.

Consultation and analysis phase

The purpose of this phase is to identify privacy issues and manage them. This should include: consultations with stakeholders; risk analysis; articulation of any problems that may exist; and a search for constructive solutions. These consultations do not need to be formal processes and can be limited to key stakeholders. Depending on the size of the project the consultation could take the form of a workshop or meeting, series of telephone interviews or writing to stakeholders.

The key deliverable for this stage is a document (PIA template, Appendix A) that details the privacy impacts identified and the solutions/actions to deal with them. The PIA template is in a form that can be published and provided to everyone involved. This is especially useful to those who will need to make changes to the design of the project due to identified issues.

Action points
- Consult with key stakeholders about potential privacy issues and detail them in the PIA template document (Appendix A, point 3). This should give a brief overview of the issue and then set out a plan for managing issues or detail solutions.

Documentation phase

The purpose of this phase is to document the PIA process and outcomes. The deliverable from this stage is the PIA report, which may draw heavily from the document produced during the previous stage, consultation and analysis. This is satisfied by the PIA template (Appendix A) to be completed for each activity. When completed these should be sent to HDTI (Coventry University) and will then be collated into a more substantial document forming the PIA report. Review dates (see following section) should be entered into the document before sending this to HDTI.

Action points

- Send a copy of the completed PIA template to HDTI (Coventry University) for the attention of Gina Sands (email preferred).

  Email: gsands@cad.coventry.ac.uk
  Address: Health Design & Technology Institute
        Coventry University Technology Park
        Coventry, CV1 2TT
        United Kingdom

Review and Audit Phase

The purpose of this stage is to ensure that any design features or changes highlighted in the PIA are implemented and are effective. The deliverable is a review or update report which could again be relatively succinct or more detailed depending on circumstances. This is included as a section in the PIA template (Appendix A, point 5). For activities lasting longer than three months the consultation information should be reviewed at regular intervals to ensure that privacy issues are being managed adequately. This should include a review of any other privacy issues that may have arisen since the previous review. Review dates should be filled in based upon the estimated start date of the activity. Depending on the timescale of the activity it may be necessary to review the information more than once. Review dates should be entered before sending the document to HDTI (in previous section) and may therefore be monitored to ensure reviews take place.

Action points

If the activity may last longer than three months, the privacy issues will need to be reviewed. Review dates for the periods shown on the PIA template (Appendix A) should have been completed in the previous section.

- Complete a review of the privacy issues to determine if anything has changed or new issues have arisen.
- After each review forward the document to HDTI (Coventry University) to allow records to be updated and review processes to be monitored. Email: Gina Sands gsands@cad.coventry.ac.uk
- Implement any new solutions or privacy management initiatives needed as a result of the review.

Privacy law compliance check

The partners must ensure that the project, the personal data that it handles, and the business processes are compliant with all relevant laws. The EU Data Protection Directive 95/46/EC will be most applicable and all activities within the DISCOVER project should abide by this. This is also due to be updated in 2012 so the project should also comply with recent developments of the directive. Other privacy laws specific to each partner country are detailed in the DISCOVER pilot project proposal (pp. 126-131) which must also be abided by. Assessing the compliance should begin at an

early stage of the project to address the legality of any proposed course of action. However, the majority of this work will normally be completed later when the project design has reached a more detailed stage. Privacy will be monitored throughout by each partner organisation with guidance from HDTI (Coventry University) in conjunction with project/work package leaders. Although the PIA focuses on checking compliance with privacy laws, organisations will also have to consider broader legal compliance as well which may differ between public and private sectors. There may also be further relevant documents, such as codes of conducts and privacy policy statements which might arise from membership of an association (such as university ethics).

An example of the potentially relevant laws and legislations can be found in the ICO PIA Handbook (link below), along with templates for checking compliance for UK partners.

http://www.ico.gov.uk/upload/documents/pia_handbook_html_v2/index.html

Ethical Checklist

The ethical checklist (Appendix B) has been developed in reference to the Social Research Association Ethical Checklist (2003). Before completing it, partners should refer to the guidance in the User Methodology Handbook, which provides guidance on good practice for the aspects of the DISCOVER project which involve participants or affect external organisations. This includes the topics of: confidentiality and privacy; consent, autonomy and choice; justice/fairness; inclusion; security; and dignity. The guidelines are written to inform partners about ethical issues within the DISCOVER project and are not designed to be rigid. These guidelines also may not necessarily point to clear answers and there may be conflicts between different ethical pointers. Any deviation from these guidelines should, however, only be made after careful consideration of the ethical issue in question.

Appendix A – Privacy Impact Assessment (PIA) Template

<table>
<tr><td colspan="2" align="center">Privacy Impact Assessment for DISCOVER</td></tr>
<tr><td colspan="2">Partner organisation: Task/activity title:
Date: Work Package:</td></tr>
<tr>
<td>1.
Give a brief outline of the task or project</td>
<td>[Example: We are conducting a focus group with informal carers discussing their skill level with ICT and the acceptability of the DISCOVER platform for learning new skills.]</td>
</tr>
<tr>
<td>2.
List the key stakeholders for this activity</td>
<td>[Example:

Participants (informal carers)
Project partner leading activity
Organisation that may have been involved with recruitment of participants e.g. charity or member group.
People that are cared for by the participants]

</td>
</tr>
<tr>
<td rowspan="4">3.
After consultation between key stakeholders, list any privacy issues that may arise during this activity and the solutions in place to manage these issues.

If necessary continue on a further sheet.</td>
<td>Privacy issue:
[Example: Collecting and storing names and contact details for participants]

Solution[s]:
[Example: Will collect only necessary information, will not disclose any details to a third party, details will be kept in a locked filing cabinet for the duration of the project and then destroyed]</td>
</tr>
<tr>
<td>Privacy issue:

Solution[s]:</td>
</tr>
<tr>
<td>Privacy issue:

Solution[s]:</td>
</tr>
<tr>
<td>Privacy issue:
Solution[s]:</td>
</tr>
</table>

4. Ensure that the activity complies with any relevant laws (i.e. The EU Data Protection Directive 95/46/EC or country specific laws detailed pages 126-131 in the pilot project proposal).	The DISCOVER project will abide by the following principles deriving from the EU Directive: o Personal data shall be processed fairly and lawfully o Personal data shall be obtained only for one or more specified and lawful purposes o Personal data shall be adequate, relevant and not excessive in relation to the purpose or purposes for which they are processed o Personal data shall be accurate and, where necessary, kept up to date. Personal data shall not be kept for longer than is necessary. o Personal data shall be processed in accordance with the rights of data subjects. o Appropriate measures shall be taken against unauthorised or unlawful processing of personal data and against accidental loss or damage to personal data. o Personal data shall not be transferred to a country or territory outside the European Economic Area (there is) an adequate level of protection for the rights and freedoms of data subjects.

5. Review and redo:

For longer scale activities this information should be reviewed at regular intervals to ensure that the solutions are being implemented and are adequate. This should include a review of any other privacy issues that may have arisen since the previous review.

If applicable to the length of this activity, insert the review dates in the boxes below. Also assign a person to take responsibility for ensuring that the review takes place and the outcome is noted below on each occasion.

Review dates:

3 Months	6 Months	12 Months	18 Months	24 Months	36 Months
[Insert date]	*[Insert date]*	*[Insert date]*	*[Insert date]*	*[Insert date]*	*[Insert date]*

Date:
Review outcomes:

Date:
Review outcomes:

Appendix B – Ethical Checklist

Ethical Checklist	Tick
1. Has relevant ethics clearance been gained from the host organisation? (E.g. University ethics clearance)	
2. Have the participants been fully informed about their proposed involvement in the project and what is expected of them? (In form of participant information sheet or using other means where necessary)	
3. Have the participants given informed consent? A good example to base this on can be found in Appendix 1 in the User Methodology Handbook.	
4. Have participants been informed that they are under no obligation to participate and can withdraw at any time (without needing an explanation)?	
5. Has every reasonable effort been made to include minority groups or those who have special requirements? o Researchers have a responsibility to make an effort to include groups of people who may otherwise be excluded due to accessibility of services; for example people who are disadvantaged due to lack of assistive technologies, communication aids or inaccessible environments. o This also applies to the exclusion of ethnic minorities due to language barriers.	
6. Are appropriate and robust data security procedures in place that will protect personal information given by participants? o All reasonable endeavours shall be made to minimise the privacy impact on the participants. This will be managed by conducting a Privacy Impact Assessment (PIA) and adhering to relevant privacy legislation. o Data Protection Laws (EU Data Protection Directive 95/46/EC and relevant laws specific to partner countries) shall be followed to ensure the protection of participant data. o Data shall be anonymised by assigning each participant a code which will then allow for personal details to be kept separate from interview proformas. o Information that is stored digitally and which could enable identification of the person concerned shall be password protected and encrypted if sent between partners.	
7. Are appropriate and robust procedures in place to ensure confidentiality of information given by participants?	

- Confidentiality of participants must be maintained throughout the DISCOVER project. - Interviews shall take place somewhere quiet and private if the participant is to be asked to provide personal or sensitive information - Carers and cared for people will be interviewed together or separately, depending on their preference. - No unnecessary questions shall be asked of the participants and any freely given information that is not necessary for the project will be not be recorded.	
8. Have relevant checks been made to ensure the safety of vulnerable participants? (i.e. CRB check or equivalent for researchers) - If working with vulnerable groups the researcher shall have a valid Criminal Records Bureau (CRB) check (UK) or equivalent in partner member's countries. - Researchers shall wear photo identification badges when visiting participants. - When visiting the homes of participants (perhaps for interviews or tasks) the length of time spent there shall be limited and agreed to with the participant prior to the visit. The participant shall also be allowed to stop or postpone a visit for any reason.	
9. Have appropriate considerations been given to ensure the safety of researchers in the field? - Researchers shall adhere to any health and safety regulations of their respective organisations. - When working outside normal hours it is appropriate to assign a contact person for the researcher to contact in case of difficulties or emergencies. - When visiting private homes it is important for the researcher to make others aware of the address and the expected time of finish. The researcher should also check in with colleagues when the visit is over so that they know the researcher is safe.	
10. Has the project been designed to ensure dignity of participants and not cause distress? - If in the presence of the cared for person then they should be included in the conversation, and not spoken about as if they were not present. - Personal data about the cared for person shall not be collected without permission, even if volunteered by the carer. - If the researcher is visiting a participant's home then they shall respect their privacy and possessions. - Subject matter and content of questions during interviews may be upsetting to some people so content should be chosen carefully. - Researchers should be wary of disturbing the relationship between the carer and the cared for person, or between participants and organisations they be affiliated with.	