ICTPSP
ICT POLICY SUPPORT PROGRAMME

DISCOVER
SKILLS FOR CARERS

User Engagement Methodology Handbook

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1. REVISION HISTORY AND STATEMENT OF ORIGINALITY

Revision History

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This deliverable contains original unpublished work except where clearly indicated otherwise.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.

2. Table of Content

3. Introduction

This handbook details the processes governing partners participating in DISCOVER to ensure the privacy and safety of carers and the people they care for is protected. It is a living document that will be developed and enhanced throughout the project's lifetime. This Handbook, (deliverable 2.1) should be read in conjunction with the DISCOVER Privacy Framework and Ethical Checklist (deliverable 2.2) and will inform the methodology for evaluation of DISCOVER platform and users (deliverable 4.3). Data collected and analysed as outlined in the Handbook will provide the basis for the impact evaluation reports (deliverable 2.5).

Partners in the four test bed sites agree to follow the guidelines outlined in the following sections and to produce the relevant documents in their native languages so that the documents are accessible to participants in this project, both carers and the people they care for. The guidelines about ethical issues within the DISCOVER project are written to inform partners. These guidelines also may not necessarily point to clear answers but deviation from these guidelines should, however, only be made after careful consideration of the ethical issue in question.

4. Ethics

4.1. Security & Privacy

Systems that are focused upon services related to healthcare are typically likely to collect, store, or use some type of personal or sensitive data. The DISCOVER solution is not specifically aimed at managing personal healthcare tasks, but the consortium recognises the potential for impacts in this area. For example, while healthcare information about an individual may not be directly collected, the types of training modules that a caregiver uses could provide inferences to the health conditions of those in his or her care. As such, the DISCOVER solution will be given the same sort of scrutiny as to ethics and data protection as would be deemed appropriate for any healthcare solution. Moreover, given that the design of the solution is intended to encourage a joint learning experience between carer and the cared-for, it is important that all sorts of users be considered in this process. In the context of this project, the consortium is very experienced in the design of systems and services to ensure that all appropriate actions are taken to:

- Design systems to provide strong data protection, and
- Provide effective levels of data protection and anonymity within the context of the pilot, including during the analysis of results

This will be accomplished mainly through the work of WP2, which will include a comprehensive survey of all ethical issues and legal frameworks at national and European level, and will ensure compliance with those frameworks, including Directive 95/46/EC (article 8, protection of personal data). This process will ensure that all members of the consortium have an understanding of their responsibilities and legal obligations to pilot participants, and ultimately, to users of the DISCOVER solution on an ongoing basis.

4.1.1. Data storage

Data collected during DISCOVER will be stored in accordance with the ethical regulations pertaining to the country where the data is collected and stored. In addition, each partner will ensure they collect, store data and transfer data between themselves and the Open University in accordance with the ethical requirements of the Open University, who will be analysing data from all four testbed sites. Data security is important to DISCOVER in order to ensure that personal information is not seen or handled by unauthorised people. A protocol will be developed that will be followed by all partners.

National data protection laws are potentially applicable. These follow from the EU Data Protection Directive 95/46/EC as enshrined within national legislation and accompanying guidelines; together with specific legislation e.g. regarding the position of patients when they are also 'data subjects'. The DISCOVER task is not assisted by the lack of an agreed EU definition of 'personal' or 'health' data. Health data is widely considered to be 'data that have a clear and close link with the description of the health status of a person'. But it has been advocated that 'personal' data that links with health status should also be included (per the European Data Protection Supervisor, 2008).

DISCOVER must, of course, be guided by the relevant data protection legislation (deriving, in each case, from the EU Directive) but, in order not to fall foul of regulatory frameworks that are imposed in respect of health (and, as indicated above, potentially, personal data) it will be necessary to seek consent (normally, though not necessarily, written) from those (people who receive care) who are included in the project. The 'cared for' person will, in other words, have primacy and he/she will need to give consent not only for him/her to be interviewed, but also for his/her carer to be interviewed. Special provisions are required to be in place where the 'cared for' person has a significant cognitive impairment. Appropriate consents (though this will need to be confirmed) should obviate the need for specific ethical approvals that could significantly delay the start of essential survey work within DISCOVER – even if personal or health data is gathered. Nevertheless, DISCOVER will be cognisant of and accord with the data protection principles deriving from the EU Directive. These are that:

- Personal data shall be processed fairly and lawfully
- Personal data shall be obtained only for one or more specified and lawful purposes
- Personal data shall be adequate, relevant and not excessive in relation to the purpose or purposes for which they are processed
- Personal data shall be accurate and, where necessary, kept up to date.

- Personal data shall not be kept for longer than is necessary
- Personal data shall be processed in accordance with the rights of data subjects
- Appropriate measures shall be taken against unauthorised or unlawful processing of personal data and against accidental loss or damage to personal data
- 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

The data and related information about participants will be collected locally in each test area (e.g. in survey responses, semi structured interviews). Good practice in social research work (SRA 2003) will be followed regarding e.g. consents, confidentiality / anonymity, use of balanced and non-leading questions, fair reporting of outcomes, safe storage (by OU) and shredding of completed proformas two years after competition of the project. Survey data will be held to assist in project evaluation. It will be shared in anonymised form to facilitate further analyses by individual project partners. The normal range of household information will be gathered.

4.1.2. Data storage on the DISCOVER Technical Platform

The DISCOVER platform data will be encrypted strongly with public key technology, and will include digital signatures, and origin and destiny certificate authentication in any transmission. All handling and storage of data will be protected with industrial-grade security technology in order to prevent to the best possible level any unauthorised access. System security enables the entity or system to protect the confidential information it stores from unauthorized access, disclosure, or misuse, thereby protecting the privacy of the individuals who are the subjects of the stored information. All people working on DISCOVER platform will be affiliated with European organizations and therefore subjects to all pertaining information misuse regulations.

All data included in the DISCOVER data repositories of different modules will be dissociated, ensuring users' data protection and confidentiality. Dissociation is a process by which personal, sensitive data - in our case, data such as name and surnames, formal education and other personal identifiers - are removed from the original source data files. Once this process is performed, data can be transferred without affecting the user's right to privacy. If necessary for other purpose, any DISCOVER related information that makes a person identifiable will not be disclosed without prior user informed consent and / or authorisation.

4.1.3. Researcher Safety

DISCOVER is concerned both for the safety of its participants and of the employees of partners who engage with participants in their homes. Protocols will be issued for those who undertake interviews - for their personal safety when in people's homes; and for their well-being when travelling from their workplace.

These protocols will include procedures for lone-worker safety and monitoring. Each partner shall be responsible for ensuring that all staff engaged in work in people's homes are appropriately

skilled and suitable for the same (i.e. not carrying any convictions for actions that may suggest unsuitability for working with vulnerable adults). **Each partner shall carry appropriate levels of employer's liability and professional indemnity insurances.**

4.1.4. Privacy Impact Assessment

A Privacy Impact Assessment (PIA) will be performed to ensure that all data protection and privacy issues are analysed in a structured approach, the framework for which will be adapted from the UK Information Commissioner's Office PIA Handbook utilising a model for small-scale PIAs. This will embody the principles that a PIA is designed to:

- *identify the potential effects that a proposal may have upon individual privacy*
- *examine how any detrimental effects upon privacy might be overcome*
  (Privacy Commissioner of New Zealand (2007, p5))

Partners need to consult the DISCOVER Privacy Assessment Framework (Deliverable 2.2) before undertaking a PIA.

4.2. Ethical Principles

Beyond the ethical issues of privacy, there is a broader range of issues that must be addressed for systems designed for use by human subjects. In particular, this project will be focused upon the needs of carers and a vulnerable population, i.e., older people that are within their care. Within this context, key ethical issues will be examined as discussed below.

4.2.1. Anonymity

The DISCOVER researchers will ensure that all collected data processed for statistical and/or scientific purposes shall also not be identifiable to the participant from whom it was gathered.

4.2.2. Dignity and independence

DISCOVER's focus is on individual growth and learning and upon the independence that this provides to participants. This is accomplished through an integrated approach to learning that provides individuals with tools that will be useful in their day-to-day work life, and which will provide for future application in many other domains of the digital society. For the cared for, it provides an effective approach to engaging in digital learning in concert with a trusted individual, further opening doors to their own independence.

4.2.3. Consent, Autonomy and Choice

Informed consent is essential as it allows the participant to learn about the project and the expectations of them before they agree to take part. It is important that a balance is struck between providing too little information that the participant is under informed or overloading them with unnecessary details. Information sheets relating to DISCOVER will be provided for participants before they agree to participate in the project. These information sheets will contain sufficient detail about the technology and the study conduct, including obligations of and potential negative and positive consequences of participation, and allow the participant to make an informed determination about participation without coercion. Consent should be gained from all participants after reading a full participant information sheet and having enough time to consider it.

It is inappropriate to withhold information that may discourage participation or mislead people about what tasks they will be asked to do. Therefore, the information sheets will include as a minimum what is expected of participants in terms of time, duration, and types of information gathered. They will also give details of privacy issues, how the information will be used and how long it will be kept for.

To encourage inclusion of a wide variety of people, information sheets will be made as accessible as possible and provided in different formats where necessary. Participant information sheets will be in large font as standard (size 14 recommended) and available in extra large print (size 18) if requested. This is due to the target audience of carers and cared for people which will often include older people who may have visual impairments. Information sheets may also be read out by researchers or made available via voice recordings. Partners will provide information sheets in languages appropriate to their target audience. Whilst care will be taken not to exclude significant minority groups from the sample on the basis of language it is important that participants are familiar with at least one of the DISCOVER platform languages.

There may be occasions when participants need to be approached through a 'gatekeeper' and with their permission. This will be especially true when dealing with vulnerable populations in special forms of accommodation. In these cases it is important to respect the gatekeeper and acknowledge their relationship with the proposed participant. However reasonable effort should be made to connect directly with the proposed participant and to give the information to them rather than the gatekeeper.

In most cases it is appropriate to ask the participant to sign a consent form to show that they have received information about the project and have agreed to take part. This consent form should be clear and concise to prevent confusion and should state clearly that the participant may still withdraw. A good example of a consent form which has been developed by the Open University is included in Appendix 1.

In some circumstances it may not be possible for the participant to sign a consent form. In this case if the participant has consented verbally (or by another communication method) then the researcher and an appropriate witness can sign the consent form on behalf of the participant and

make the circumstances clear. A consent form must also be signed by the cared for person before the carer can provide any personal information about the cared for person.

If the proposed participant has a cognitive impairment it is important to ensure that the participant understands what it means to be involved in the project. This might be achieved by asking them questions about their participation after the research has been explained, this will show whether the participant has fully understood or not. If the participant does give consent it is good practice to give them time to talk it over with family or a carer before starting the project in case they then wish to withdraw. It is not appropriate to approach people to participate in the project if they have significant cognitive impairments.

4.2.4. Objectivity

Objectivity will be pursued in the research design, data analysis and interpretation, peer reviews, audits, staff decisions, and other aspects of research where objectivity is expected or required. Measurement tools (surveys, etc.) will be designed and tested prior to the beginning of each phase to ensure that objective results will be collected.

4.2.5. Nonmaleficence and Safety

Nonmaleficence imparts an obligation to not inflict harm intentionally, and safety involves freedom from danger. Every participant and system user must be guaranteed the right to be safe and free of harm while using the DISCOVER platform. The researcher is obligated to protect participants as far as possible from any potential harm that could result of their involvement in the project. All harms and risks must be minimized, with special precautions being taken for vulnerable elderly participants. Harm to participants may occur through stress, loss of self-esteem, and creating friction within relationships (i.e. carer and cared for). Self-esteem can be affected when potential participants are overlooked or excluded from participation. Therefore it is also important to attempt to include minority groups wherever possible.

The learning modules that provide information for teaching carers specific skills and techniques must support these goals, and a process will be defined to ensure only professionally validated information, that does not require personal supervision of carers, is disseminated.

4.2.6. Self-determination/Autonomy

Participants will be advised that participation is voluntary (via informed consent) and there will be no pressure on the participant to join the project, either by the researcher or a third party. Participants will also be advised that they are free to withdraw at any time without any requirement to provide a reason or to decide not to answer a particular question/questions. They also have the right to control the data (such as text, audio, video and photographs) that pertains to them and, if they chose to withdraw from the project, they can request that any recently collected data is removed.

4.2.7. Inclusiveness

In addition to these key ethical principles, the issue of **inclusion** (based upon principles of justice and equality) is of particular interest in the design of the DISCOVER solution. A key objective of the entire DISCOVER solution is to address digital inclusion, and through this, potential for greater socio-economic inclusion for individuals who are often left out of technological advances because of their role in providing informal care. These carers are predominantly female, and frequently, as members of an extended family, receive little or no financial remuneration for the services they provide. Beyond this primary level of focus upon inclusion, it is anticipated to also enhance e-Inclusion for older people who are in the care of participants by involving them jointly in some of the training that is performed with the carer. In the design of the solution, care will be taken to use *Design For All* principles *(*http://www.designforall.org/en/dfa/dfa.php) to ensure accessibility of the technology itself.

Once individuals are recruited, attention will be paid to enabling participation. For all participants flexibility of appointment times and length of interviews may be a factor as they may have many other obligations in their lives. The partners have discussed interviewing the carer and the cared-for person separately, to ensure their confidentiality and privacy, but feel this is inappropriate as the cared-for person may be very frail. Also, the focus of the project is on the carer's own developing knowledge and skills, and the extent to which they have shared this knowledge and skills with the person they care for. Therefore the carer and the person for whom they provide care will be interviewed either together or separately, depending on their preference. Meeting costs for travel to interview venues is encouraged to allow participants with low incomes to be included.

5. Ethical Regulations across the 4 test bed sites

Each partner agrees to abide by the ethical regulations pertaining to their country and to gain ethical approval from their own country as necessary. The next section outlines the ethical regulations for each country involved in the development of the DISCOVER platform or as a test bed site.

5.1. Greece

5.1.1. Greek Regulatory Framework

The Data Protection Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 serves as the reference text for data protection issues throughout Europe, and also requires that each Member State set up an independent national body responsible for the protection of these data. Law 2472/1997 protects individuals with regard to the processing of personal data. According to article 15, the Personal Data Protection Authority is responsible for the implementation of this law and all other regulations pertaining to the protection of individuals from the processing of personal data. Law 2472/1997 refers to the protection of personal data and privacy in the electronic telecommunications sector and amendment of law 2472/1997.

5.1.2. Data collection

According to article 7, "The collection and processing of sensitive data is prohibited". Exceptionally, the collection and processing of sensitive data, as well as the establishment and operation of the relevant file , will be permitted by the Authority , when at least one of several requirements are met, including:

- The data subject has given his/her written consent (7.2a).
- Processing is carried out exclusively for research and scientific purposes

First of all, the Controller must notify the Authority in writing about the establishment and operation of a file or the commencement of data processing (7.3), always provided that anonymity is maintained and all necessary measures for the protection of the persons involved are taken (article 7.2f). In the following, the Authority will grant a permit for the collection and processing of sensitive data, which will be issued for a specific period of time, depending on the purpose of data processing, and which may be renewed upon request of the Controller, as well as a permit for the establishment and operation of the relevant file (7.3, 7.4).

The permit, a copy of which will be kept by the Authority, will contain information including the name and address of the Controller and the place where the file is established, the categories of personal data which are allowed to be included in the file, the time period for which the permit is granted, the terms and conditions, if any, imposed by the Authority etc. Any change in the above must be communicated to the Authority and may entail the issuance of a new permit (7.5, 7.6, 7.7).

5.2. Ireland

The main Irish law dealing with data protection is the Data Protection Act 1988. The 1988 Act was amended by the Data Protection (Amendment) Act 2003. A pre-certified restatement of the law is available here. The 2003 Amendment Act brought national law into line with the EU Data Protection Directive 95/46/EC. All Sections of the Acts are in force, except Section 4 (13) (enforced subject access).

5.2.1. Electronic Privacy Regulations

The ePrivacy Regulations 2011 (S.I. 336 of 2011) deal with data protection for phone, e-mail, SMS and Internet use. They give effect to the EU e Privacy Directive 2002/58/EC (as amended by Directive 2006/24/EC and 2009/136/EC).

http://dataprotection.ie/ViewDoc.asp?fn=%2Fdocuments%2Flegal%2FLawOnDP%2Ehtm&CatID=7&m=l

5.3. Spain

DISCOVER project falls under the regulations of the Spanish Law through the "Ley Orgánica 15/1999 de Protección de Datos" of 1999. The Spanish Data Protection Authority ("Agencia de Protección de

Datos") provides administrative registration of files, and in the autonomous community of Catalonia, the Catalan Agency of Data Protection has authority over personal data treated by local administrative bodies and universities. Furthermore, on the clinical side, the pertinent regulations are the "Ley Básica reguladora de la Autonomía del Paciente y de derechos y obligaciones en materia de información y documentación clínica [A14]" and, its Catalonian counterpart

5.3.1. Research related regulations:

Law 41/2002

The object of Law 41/2002 of 14 November 2002 is the regulation of the rights and obligations of patients, users and professionals, as well as of public and private healthcare centres and services, with regard to the autonomy of the patient and of clinical information and documentation.

The basic principles are that:

1. The dignity of the individual, the respect for the autonomy of his/her will and for his/her privacy will orientate the obtaining, use, archiving, keeping, and transfer of clinical information and documentation.
2. All actions require the prior consent of the patients or users, this consent will be given in writing as foreseen in the law.
3. The patient or user has the right to decide freely between the clinical options available.
4. Every patient or user has the right to refuse treatment, except in the cases determined in the Law.
5. The patients or users have the obligation to give information about their health in a trustworthy and truthful fashion.
6. Every healthcare professional is obligated to lend his/her services correctly, and to comply with obligations regarding clinical information and documentation, and to respect the decisions of the patient.
7. The person that produces or has access to clinical information and documentation is obliged to keep it in confidence.

Rights that are regulated:

1. Right to healthcare information (the holder of the right is the patient, though people related to him/her will also be informed. These relations may be familial or of fact, according to the permission of the patient)
2. Right to epidemiological information.
3. Right to privacy.
4. Right to information for the choice of doctor and centre.
5. Right to access to clinical history.
6. Rights related to the keeping of clinical history.

In this law, the respect for the autonomy of the patient is regulated via informed consent, expressing its limits, the conditions of the information that it must contain, whether it be verbal or

written. This law considers clinical history, its definition, archiving and conservation, as well as the content that it must include and it use. Access to it for judicial, epidemiological, public health, research or teaching reasons is subject the Organic Law 15/1999 and the Law 14/1986. Likewise the discharge of the patient, discharge report, and the issue of medical certificates are regulated.

Trial Approval Process

In 1990, with the introduction of the Ley del Medicamento, “Clinical Research Ethics Committees (CEICs)” were formally established in order to assess methodological, ethical and legal aspects of the protocol as well as the benefit/risk balance of all clinical trials to take place in Spain. The authority that authorises each clinical research ethics committee is the regional government. There are 18 CEICs throughout Spain. According to the Spanish law [223/2004], a Clinical Research Ethics Committee must approve all research projects involving human participants.

The procedure for authorising a clinical trial in Spain is the following:

- For all trials, an application must be submitted to all CEICs covering the areas where the trial will be performed (between the 1st to the 5th day of the same month).
- An application must be submitted to the responsible authority, the Spanish Medicines Agency (Agencia Espanola de Medicamentos y Productos Sanitarios - AEMP).
- There is an online application through the Internet where all involved committees must provide their comments on the protocol.
- Finally, after assessing the comments from all the involved committees, the 'reference CEIC' provides its final 'single opinion'.
- There is also a requirement for the budget of each study, and each site, to be submitted to the CEIC.
- The established timelines for the assessment of single- and multi-site studies is 60 days according to the regulations.
- The database will be also registered on the Spanish Data Protection Agency (Agencia Española de Protección de Datos), fulfilling the requirement to notify this Agency of transfers of personal data between EU member states.

Other regulations:

Scientific Good Practices Code, by the CSIC (Spanish Highest Board for Scientific Research). The CSIC Presidency, commissioned the Ethics Committee to design this Code of Good Scientific Practices, bringing together a set of rules, principles, compromises, declarations and/or recommendations applicable to any research kind. This Code calls for basic moral principles, helping its development and achievement. The Good Practices Code should be the instrument to generate and guarantee the integrity and ethical quality of scientific research developed in the CSIC.

This code collects good practices in scientific research, involving:

Principles for the research activity
The researcher as a professional of science
Scientific Publications: Oral and printed
Institutional background
Legal Regulations
Ethical codes for each profession
International codes, as the Helsinki Declaration and the Belmont Report.

5.4. The Netherlands

In The Netherlands there is no need for special approvals for the research work necessary for DISCOVER. The trials can start anytime. In the course of the DISCOVER trials there will be no collection or storage of personal data by ASTRA. The participants will decide themselves what personal characteristics or data they want to share.

On line security and data protection will be handled according to the rules and guidelines described in the Wet bescherming persoonsgegevens (Wbp: Law to protect personal data). The 'College Bescherming Persoonsgegevens (CBP)' i.e. the Dutch Data Protection Authority (DPA) http://www.dutchdpa.nl/Pages/home.aspx is responsible for the monitoring of this law. Localised trials will be headed by local authorities and thus any collecting and storage of data will be protected by the rules and regulations that all Dutch municipalities have regarding personal data (Wet gemeentelijke basisadministratie persoonsgegevens, Wet GBA).

Where necessary the ECG Centrum voor Ethiek en Gezondheid (Centre for Ethical and Health issues) and the NEN, Netherlands Normalisation institute will be consulted. The latter are responsible for monitoring the standards and protocols regarding online security and data protection in The Netherlands; for instance the 'Code voor Informatiebeveiliging' which is the Netherlands version of the British Standards 7799: NEN ISO 27001 and NEN ISO 27002 are applicable. Laws concerning medical research with participants and patients are WMM and WGBO. These give guidelines for scientific research as a whole and the protection of people who cannot speak for themselves. These guidelines will be used when applicable.

5.5. United Kingdom

5.5.1. Key Legislation

Key legislation in the UK that is pertinent to the project is enshrined in the 1998 Data Protection Act. Eight data protection principles apply viz. (in brief):

1. Personal data shall be processed fairly and lawfully
2. Personal data shall be obtained only for one or more specified and lawful 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, where necessary, kept up to date.
5. Personal data shall not be kept for longer than is necessary
6. Personal data shall be processed in accordance with the rights of data subjects
7. Appropriate measures shall be taken against unauthorised or unlawful processing of personal data and against accidental loss or damage to personal data
8. Personal data shall not be transferred to a country or territory outside the European Economic Area (where there is) an adequate level of protection for the rights and freedoms of data subjects

There is, within the legislation an imperative to give special attention to sensitive data of the kind that relates to people's home circumstances, their health status, personal relationships and the like. Specific guidance on health data applies … though, as yet, there is no clear definition (at a UK or EU level) of the boundaries of 'health data' in relation e.g. to personal lifestyles.

5.5.2. User Engagement

No legislation provides guidance on (or requirements for) effective user engagement in social research. Good practice is, however, set out in the guidelines of the (UK) Social Research Association (see http://www.the-sra.org.uk/documents/pdfs/ethics03.pdf). These point to core principles associated with researchers'

- obligations to society – e.g. requiring researchers to work responsibly 'in light of the moral and legal order of the society in which they practice' including adherence to high standards when gathering, analysing data, and disseminating findings.
- obligations to funders / employers – to be both 'clear and balanced' and maintain standards associated with professional integrity.
- obligations to colleagues - associated with appropriate professional behaviour including the use of methods that are open to review and take account of the safety and security of researchers.
- obligations to subjects – protecting them from 'undue harm' and ensuring voluntary and 'fully informed' consent before participation.

5.5.3. Wider Ethical Perspective

The above are part of a wider context of research that has different ethical dimensions and can underpin what is regarded as best practice. We will be guided by the principles determined in the EU funded 'ICT for ALL project' viz. that (in summary) good practice is

a) represented by ways of working, based on a set of principles, accordance with which helps to fulfil aims and objectives associated with appropriate political, economic and social goals.
b) promotes what is right, not what is expedient.
c) is informed, relevant and potentially innovative.

d) contributes to the health, well-being and inclusion of all people.
e) acknowledges and addresses disadvantage encountered due to environmental factors, disability or prejudice.
f) wherever appropriate, challenges the status quo and raises questions about the way things have been done in the past.
g) accessible and able to be shared so that others can adopt it and adapt it.

On the edge of our health and wellbeing interests are the principles of biomedical ethics developed by Beauchamp and Childress (2001). These are important in the field of medical ethics and affirm four principles:

- respect for autonomy;
- nonmaleficence;
- beneficence; and
- justice.

Each of these reach into the areas which DISCOVER will consider. Not that addressing each of the four will necessarily resolve tensions between ethical principles – indeed, an example of an ethical difficulty inevitably arises in work with carers when their beliefs about what is needed or appropriate may be different from those of e.g. a 'cared for' person with a cognitive impairment. But the pursuit of a balance between the four principles is frequently evident in key strategic documents – these affirming, on the one hand, the need for person-centred services (and *ipso facto* pointing to the need to support personal autonomy and choice) but, on the other hand, recognising the right of the carer to have their voice heard. Such strategic documents include the UK Strategy for Older People ('Opportunity Age') and equivalent strategies produced by the devolved governments. Associated with these is the perceived moral and ethical obligation (rooted, arguably, in humanitarian and faith based principles) to provide care and to facilitate the inclusion of people with support needs in economic and social life. Of note, and especially important in these and wider contexts, is the 2005 Mental Capacity Act which seeks to protect the position of people with limited or no capacity

6. Ethics Approval

Ethical Approval for the project as a whole has been given by Birmingham City Council. Outline ethics approval has been given by the Open University, who will be analyzing the data, and full approval will be sought once the information sheets, consent forms, outline questionnaires and interview guides have been agreed by the consortium. These documents will be developed by the Open University and translated by the other partners into their native languages. The following partners: AUTH and INTRAS will seek ethical approval from their relevant committees before they commence recruiting participants to DISCOVER. In addition, BCU and the OU will secure ethic approval for iterative and beta testing of the DISCOVER materials before they are used by participants in the DISCOVER project.

6.1. Legal and Ethical Checklist

A legal and ethical checklist (Deliverable 2.2) has been developed and the pilot implementation will be reviewed against it. This list will give special consideration to ethical issues (noted above) – and to the position of carers when the 'cared for' person has limited cognitive ability. This task will also take into account the requirements of national equality legislation.

6.2. Risks

The main focus of DISCOVER is on digital skills and background health knowledge that improves understanding within a caring context rather than on medical/nursing skills that require supervision, so neither carers or cared for adults should be at risk. To mitigate against the risk of carers and the people they care for being misinformed, all DISCOVER materials relating to caring skills and knowledge of health conditions will be reviewed by healthcare experts prior to incorporation into the DISCOVER learning pathway. Some carers may benefit from support workers re digital skills initially but this is unlikely through the later stages of the project as learning is primarily online.

6.3. Project Advisory Board.

This Board will act as a guardian for DISCOVER, reaffirming the ethical framework and helping to shape the 'User Engagement Methodology' and other aspects of the project. Members of the Advisory Board will be drawn from local Steering Groups – including key statutory sectors, organisations of and for older people, carers' organisations, and older people themselves in the test areas of the countries concerned.

7. European Commission: ethical regulations

7.1. Overview

In addition to each country complying with their own nation's ethical frameworks and the ethical requirements of the Open University's Ethical Committee, the DISCOVER partners will comply with the ethical framework of R&D and CIP programmes of the Commission.

The partners also undertake to abide by the regulations governing clinical research (see footnote[1]) and not to carry out research under this project involving any of the following activities:

(a) research activities aiming at human cloning for reproductive purposes,
(b) research activities intended to modify the genetic heritage of human beings which could make such change heritable, and
(c) research activities intended to create human embryos solely for the purpose of research or for the purpose of stem cell procurement, including by means of somatic cell nuclear transfer.

7.2. Ethical Review

DISCOVER partners shall provide the Commission with a written confirmation that it has received favourable opinions of the relevant ethics committees and, if applicable, the regulatory approvals of the competent national or local authorities in the country in which the research is to be carried out before beginning any Commission approved research requiring such opinions or approvals. The copy of the official approval from the relevant national or local ethics committees must also be provided to the Commission.

[1] **Clinical Research**
The Commission shall never be considered as a sponsor for clinical trials in the sense of Directive 2001/20/EC of the European Parliament and of the Council of 4 April 2001 on the approximation of the laws, regulations and administrative provisions of the Member States relating to the implementation of good clinical practice in the conduct of clinical trials on medicinal products for human use. Annex I shall indicate the name(s) of any such sponsor(s). For trials not covered by Directive 2001/20/EC, Annex I shall indicate the name of the person or organization that is responsible

8. DISCOVER contacts for ethical questions

8.1. Greece

Prof. Panagiotis D. Bamidis
bamidis@med.auth.gr

8.2. Ireland

Andrew McFarlane
andrew.macfarlane@casala.ie

8.3. Spain

Victoria de Vena
victoriadevena@hotmail.com

8.4. The Netherlands

Roul Wessels
roulwessels@astracom.nl

8.5. United Kingdom

Malcolm Fisk
MFisk@cad.coventry.ac.uk

9. Participants

9.1. Formal carers

A formal carer is identified as a person who is employed in a professional care capacity that delivers services of care to an individual or group of individuals and who is paid.

9.1.1. Inclusion criteria

This is dependent on the test-bed site as each partner is bringing a unique perspective but the following criteria are common.

Each formal carer participating in the DISCOVER learning pathway must be

- Over 18
- Eligible under the country specific inclusion criteria
- Providing home care for at least one older person who would benefit from participating in the project (over 65)

Country specific inclusion criteria are as follows

Greece
Carers must be in the 18 – 55 age group (70% of all carers in Thessalonica).

Spain
Carers must be in the 18 – 65 age groups of carers (80% of all carers in Spain)

The Netherlands
Carers must be in the 18 – 75 age group (75% of all carers in The Netherlands)

United Kingdom
Carers must be in the 18 – 64 age group (75% of all carers in Birmingham)

The DISCOVER project is aimed at domiciliary care workers who are most likely to benefit from these materials.

9.1.2. Exclusion criteria

This is dependent on the test-bed site as each partner is bringing a unique perspective but the following criteria are common.

Formal Carers will be excluded from in the DISCOVER learning pathway if they are

- under 18
- over the maximum age given in the country specific inclusion criteria
- not providing home care for at least one person who is over 65 and can benefit from the project

Country specific exclusion criteria are as follows:

Greece/Spain/The Netherlands

- no specific exclusion criteria

United Kingdom

- Specialist carers e.g. intensive care, geriatric specialist care,
- Carers who only provide services in a hospital or surgery setting

9.2. Informal carers

An informal carer is a care giver that cares for an individual or group of individuals in some capacity but it is not their main profession and may or may not get paid to undertake this role. The carer in this capacity would generally be a relative or friend of the person.

9.2.1. Inclusion criteria

This is dependent on the test-bed site as each partner is bringing a unique perspective but the following criteria are common. Each informal carer participating in the DISCOVER learning pathway must be:

- Over 18
- Eligible under the country specific inclusion criteria
- A Carer of an older person (over 65)
- Not provide specialized medical care to the cared for person
- The person being cared for must have low dependency needs, for example require assistance with:
    - Activities of daily living (ADLs) such as personal hygiene, meal preparation etc
    - Extended activities of daily living (EADLs) such as shopping, finances, attending healthcare appointments
    - Some nursing activities such as blood glucose monitoring, stoma care, PEG feeding
    - Not require specialized medical care from the carer

Country specific inclusion criteria are the same as given for formal carers (section 9.1.1)

9.2.2. Exclusion criteria

This is dependent on the test-bed site as each partner is bringing a unique perspective but the following criteria are common.

Informal Carers will be excluded from in the DISCOVER learning pathway if they are

- under 18
- over the maximum age given in the country specific inclusion criteria
- caring for a person who is under 65
- caring for a person with high dependency needs, e.g specialized medical care

Country specific exclusion criteria are as follows

Greece/Spain/The Netherlands

- no specific exclusion criteria

United Kingdom

- Carers who only help in a hospital or residential home setting

10.Recruitment

10.1. Informal carers

Partners will work with carer support and community organisations that support informal carers to approach testbed participants. This will ensure that communication with informal carers happens through a trusted intermediary and that venues for meetings are well-known. Invitation letters, fact sheets, posters, and informed consent will be in plain language, at appropriate level of information, pointing out benefits tailored to informal care situation and will come recommended by the established support organization. Testbed participants sample to be monitored to represent city/national situation.

10.2. Formal carers

Formal carers will be recruited through their Employers. Where consortium partners are themselves employers of formal carers, these may be engaged in the testbed. All partners have established links to care employers that are supportive of the project and will engage their employees. In addition, other third party carer employers will be engaged if appropriate. Invitation letters and informed consent will be in agreement with employer, might point out professional benefits and use professional language

Each partner will be responsible for recruiting formal and informal carers to the DISCOVER learning pathway, as detailed below (sections 10.2.1- 10.2.5).

10.2.1. Greece

Participants will be recruited from the following institutions that have a large number of domiciliary care workers.

- Charisseio Home for older people in Thessalonica
- http://users.forthnet.gr/the/xariseio/edok4.html
- 4 Day Care Centres in Thessalonica for older people with Alzheimer's http://www.alzheimerhellas. gr/english.php
- Prefecture of Thessalonica with several Open Care Community centres (KAPI).
- Private homes.

Recruitment targets: Informal Carers – 60 // Formal carers – 40

10.2.2. Spain

Informal carers will be recruited from the following institutions

INTRAS' Centres:

- Psychosocial Rehabilitation Centre (Zamora)
- Community support teams (itinerant) (Zamora)
- Day care centres and Residence facilities (Zamora)

Other stakeholders:

- Hospital of Zamora (Zamora)
- Social Action Centre of Zamora
- Virgen del Canto Residence Facility (Toro-Zamora)
- HH. de los Pobres Residence Facility (Valladolid)

Formal carers will be recruited from the staff of INTRAS' day care centre and the Toro residence facility. These samples will be increased by other candidates interested in participating, identified though INTRAS CV database and through public advertisements at INTRAS' web page, existing social support networks, newspapers, and newsletters.

Recruitment target: Informal Carers – 80 // Formal carers – 20

10.2.3. The Netherlands

Informal carers will be recruited through the following local and regional organisations, organised by the local authorities:

- Homecare organisation(s)
- Wmo Platforms (elderly)
- Informal care platforms

- Support and information centres for informal Carers
- Advisory Board of Senior Citizens
- Unions of the Elderly
- Computer trainings organisations for the elderly
- Public Library and special focus groups of/for informal carers.

Formal carers will be recruited through the following organisations:

- Netherlands Institute for Health Promotion (NIGZ),
- Buurtzorg Nederland (BZN)

Recruitment target: Informal Carers 75 // Formal Carers 25

10.2.4. United Kingdom

Informal carers will be recruited through:

- the Birmingham Carers centre
- local libraries
- Black and Minority Ethnic (BME) champions

Formal carers will be recruited through:

- The Adult & Communities Directorate, focusing on the Personal Assistants scheme

Recruitment target: Informal Carers – 75 // Formal carers –25

11.Informed Consent

The point regarding consent was noted above (see section 4.2.3). Information sheets and consent forms for participants will be developed that draw on different sources of guidance as a 'foundation' in order to ensure clear relevance to DISCOVER.

12.Research Methods: Overview

The data and related information about participants will be collected locally in each test area. A protocol for administering questionnaires and carrying out focus groups and interviews will be developed to ensure consistency across the 4 testbed sites.

Good practice in social survey work will be followed regarding e.g. consents, confidentiality / anonymity, use of balanced and non-leading questions, fair reporting of outcomes, safe storage (by OU) of and shredding of completed proformas at the end of the project. Survey data will be held to assist in project evaluation. It will be shared in anonymised form to facilitate further analyses by individual project partners.

12.1. Researcher Safety

DISCOVER is concerned both for the safety of its participants and of the employees of partners who engage with them in their own homes. Protocols will be issued for those who undertake the interviews - for their personal safety when in people's homes; and for their well-being when travelling away from their workplace.

These protocols will include procedures for lone-worker safety and monitoring. Each partner shall be responsible for ensuring that all staff engaged in work in people's homes are appropriately skilled and are suitable for the same (i.e. not carrying any convictions for actions that may suggest unsuitability for working with vulnerable adults). **Each partner shall carry appropriate levels of employer's liability and professional indemnity insurances.**

13.Research methods: Carers' needs

13.1.1. Focus groups

Carers in each test-bed site will be invited to attend focus groups to establish their needs to develop digital, caring and employability skills. This will include establishing their preferred technology for learning and acquiring information, their current level of skills, their interest in acquiring greater understanding, knowledge and skills concerning the health condition of the person they care for and the value they place on developing their employability skills.

13.1.2. Initial evaluation: questionnaires

Carers' needs will also be assessed through the initial evaluation questionnaires (See section 14.4).

14.Research methods: Development of DISCOVER materials

14.1. Iterative design testing

The project will adopt an iterative design process (such as the Cambridge University Inclusive Design Model http://www.inclusivedesigntoolkit.com). BCU and the OU will set up user focus groups and individual trials in the UK for testing DISCOVER products (e.g. website, learning content, device access) during the iterative design process. These carers and older people will not participate in the DISCOVER learning pathway

14.2. Translation of DISCOVER materials into test-bed languages

Each test bed partner will decide which of the various DISCOVER materials they wish to offer to their participants. Partners agree to translate their chosen DISCOVER materials, back-check the translations with BCU and then undertake trials of the materials as outlined below.

14.3. Focus group beta testing

Each test-bed site will arrange for small focus group trials of DISCOVER products before full deployment and feed their comments back to BCU and AUTH to enable refinement of the materials. These carers and older people will not participate in the DISCOVER learning pathway.

15.Research methods – Impact assessment

Partners agree to translate the questionnaires into appropriate language, back-check the translations with the Open University and then follow the protocol for administering the questionnaires and carrying out the interviews. Data collected and analysed as outlined below will provide the basis for the impact evaluation reports (deliverable 2.5).

15.1. Test evaluation methodology with volunteer carers/older people

Prior to the main study commencing, the questionnaires described below will be piloted in the UK. The questionnaires will be initially in English but as Birmingham comprises a culturally diverse population, they may also be translated into other languages. Following analysis of the findings, the questionnaires will be revised to ensure they are appropriate instruments for the project.

15.2. Implement pilot evaluation in each testbed in local language

Partners in the test-bed countries, who are competent in research methods and in using English, will translate the questions into appropriate languages and back-check the translations with the OU. Translation tools, such as Google Translate, may also be used to assist in this process.

15.3. Apply questionnaire and analyse pilot phase evaluation

Following analysis of the findings, the text of the questionnaires will be revised as necessary to ensure they are accessible and understandable for participants in each country.

15.4. Initial Evaluation

Once potential participants in each country have been identified, both the carer and one person they care for will be asked to complete the individual indepth questionnaires described below.

Equivalent numbers of carers (or all carers over a three month period, whichever is most practicable in each country) attending Carers centres or similar in each country, and/or the focus groups will also be asked to complete this questionnaire to give a broader perspective of the digital skills and caring skills of formal and informal carers in each country. These carers will not participate in the DISCOVER learning pathway. This data will give a baseline for assessing the impact of the project.

15.5. Survey: initial questionnaire visual data collection

Indepth questionnaires will be developed by the Open University, based, in part, on the Eurlife and European Quality of life survey indicators, to provide robust comparisons with national data held for each country. In addition, indicators for the Multidimensional Social Exclusion Index will be incorporated into the questionnaires to measure the impact of DISCOVER on social inclusion.

The questionnaires will provide:

- Demographic details such as age, gender, hours worked outside the home, hours worked as an informal/formal carer, family income etc.
- Details of participants current knowledge and use of digital technologies, e.g. email, internet shopping, access to health services
- Participants perceived value of digital technologies
- Self assessment of their current quality of life through adaptation of the Eurlife and European Quality of life survey and dedicated and well-quantified questionnaires such as the Winconsin Quality of life Index , which takes into account the perspectives of both the person being cared for and their carer. This will also include their perceived levels of stress

and ill health as 51% of carers in the UK in 1998 reported being treated for a stress-related illness since becoming a carer [Carers UK (1998) Ignored and Invisible - Carers experience of the NHS] and a recent study [Carers UK (2004) In Poor Health: The Impact of Caring On Health], found that carers providing high levels of care were twice as likely to suffer ill health as non-carers.

- Assessment of their knowledge of digital and care skills and common health conditions such as dementia, heart disease, diabetes.

This is not an exhaustive list of indicators and the evaluation methodology will be developed further during the project to reflect findings from new publications.

15.6. Initial Interviews

25 participants from each country, and the person they care for, will be invited to participate in semi structured interviews to gain a rich understanding of their current levels of digital and care skills and their perceived quality of life. This data will be available during the early stages of the test bed pilots.

The take up of new technologies by formal and informal carers in the test bed countries will be assessed through analysis of the above questionnaires and semi structured interviews.

15.7. Final Evaluation

15.7.1. Survey: final questionnaire visual data collection

In addition to the indicators of quality of life described above, the questionnaires administered initially will be adapted to evaluate the following indicators of success

For informal carers	
by assessment	*by self assessment*
• improved digital literacy • improved care skills • improved understanding and knowledge of common health conditions	• increased leisure time • improved access to services • reduced levels of caregiver stress • improved health • improved work-life balance • increased take-up of paid employment
For formal carers	
by assessment	*by self assessment*
• improved digital literacy • improved care skills • improved understanding and knowledge of common health conditions	• improved work-life balance • enhanced opportunities for paid employment
For the person being cared for	
by assessment	by self assessment
• improved digital literacy • improved understanding of their health conditions	• improved access to services • improved health • reduction in GP visits • reduced social isolation

This is not an exhaustive list of indicators and the evaluation methodology will be developed during the project to reflect the needs identified by the carers and the content of the training materials.

15.7.2. Assessment quizzes (embedded in each online learning activity)

Assessment will be carried out by using quizzes (interactive online questions). These will be embedded in each online learning activity that participants undertake before starting the activity and on completion to enable evaluation of the following indicators of success:

For carers (informal and formal)

- improved digital literacy
- improved care skills
- improved understanding and knowledge of common health conditions

For the person being care for

- improved digital literacy
- improved understanding of their health conditions

This is not an exhaustive list of indicators and the evaluation methodology will be developed during the project to reflect the needs identified by the carers and the content of the training materials. Only cared-for people who interact directly with the online materials will engage with the online quizzes so data from these individuals may be limited. Data collected and analysed as outlined above will also inform the methodology for evaluation of DISCOVER platform and users (Deliverable 4.3).

15.7.3. Interactive data from DISCOVER platform software

DISCOVER plans to process and transmit data using protected automated data files subject to the supervision of different controllers. Modules working together on the DISCOVER platform will share information and consequently, it will be sent, received, stored or gathered by different components of the platform. Accordingly, the necessary measures will be taken to ensure data protection of the highest grade.

- Users' personal information regarding their skills, educational level or other relevant private information will be treated according to the privacy principles outlined in section 4.1.1 and under the consent of the involved users.

- All data included in the DISCOVER data repositories of different modules will be dissociated (see section 4.1.2), ensuring users' data protection and confidentiality.

Data will be collected automatically via the various technologies that comprise the DISCOVER platform for learning e.g.MOODLE, Mahara, VCC, Open Labyrinth, SCORM Compliant Learning Objects and extracted by technical experts to assess the extent to which the teaching and learning, and the technologies used to deliver this learning, met user requirements. It will include measures of the

- Ease of access to learning resources – both formal and informal
- Uptake of learning through different platforms
- Preferred choice of channels accessed
- Registration and completion of modules

This data will inform the midterm review (see WP2 User Engagement) and will be triangulated with the end of project questionnaires and interviews undertaken in WP2 User Engagement, to provide independent measures of success to mitigate possible biases of self-report questionnaires. Data collected and analysed as outlined above will inform the methodology for evaluation of DISCOVER platform and users (deliverable 4.3).

16.References

Design for all foundation at http://www.designforall.org/en/dfa/dfa.php Accessed 06/07/12

Privacy Commissioner of New Zealand (2007) *Privacy Impact Assessment Handbook* available from http://privacy.org.nz - Accessed 06/07/12

Social Research Association (SRA). 2003. *Ethical Guidelines.* http://www.the-sra.org.uk/documents/pdfs/ethics03.pdf - Accessed 25/05/2012.

17.Appendix 1 – Informed Consent Form

Digital Skills for Carers bringing Opportunities, Value & Excellence (DISCOVER):

Participant Consent Form

Please initial box

1. I confirm that I have read and understand the information sheet for the above project. I have had the opportunity to consider the information, ask questions and I have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my care or legal rights being affected. ☐

3. I understand the conditions under which personal information collected in this study will be confidential, anonymous and protected. ☐

4. I give permission for information, including the use of quotations, collected in the questionnaires, audio or video recordings to be used in any presentation of the research findings with the understanding that my anonymity will be assured, unless I waive my anonymity in writing. ☐

5. I give permission for photographs and video recordings taken during the project, including stills taken from video recordings of group meetings, to be used in any presentation of the project including the project website. ☐

6. I agree to take part in the above study.

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Name of participant	Date	Signature
----------	----------	----------
Name of person taking consent	Date	Signature

18. Appendix 2 – Focus Group Briefing: Identifying Carers' Needs

Focus Groups: Identifying Carers' Needs

Introduction

To help to identify carers' needs, we intend to carry out focus groups to gain the views of 16-20 carers in each test bed country: Greece, Spain, The Netherlands and the UK.

The proposed time line for implementation is given below.

	Calendar month	Sept 2012	Oct 2012	Nov 2012	Dec 2012	Jan 2013
	Project month	6	7	8	9	10
Activity	**Action**					
Focus group briefing	**OU test bed partners**					
Privacy Impact Assessment & Ethical checklist	**HDTI test bed partners**					
Set Focus group dates	**test bed partners**					
recruit participants & hold focus groups	**test bed partners**					
Write reports of Focus groups	**test bed partners**					
Send copies of reports to OU	**test bed partners**					
Update overall report	**OU**					
Any additional data to OU	**test bed partners**					

Facilitating the focus groups

(Allow 2.5 hours or 3 hours if including lunch)

Ideally, each test bed country should undertake 2 focus groups, with each focus group consisting of 8 -10 participants who have experience as either formal or informal carers. Unlike the inclusion criteria for the participants in the test-bed pilot studies, the only criteria for inclusion in these focus groups is that each participant should be caring for a person currently or have been a carer previously. There are no restrictions on the age of the cared-for person, or on the carers' specific caring roles, but the carer must be aged over 18. To capture the range of carers' experiences with technologies and to identify their needs the focus group will ideally include participants who currently use technologies, such as PCs or smart phones, and those who are unfamiliar with such equipment.

The aim of the focus group is to elicit the carers' perspectives on

- Their caring situation
- Their use of digital technologies
- Their level of digital skills
- The value of technologies in assisting carers
- The use of technologies to improve the quality of life of carers and the people they care for
- The specific digital skills they would like to acquire
- The skills/information they feel would assist them in their caring roles/future employment

Preparation

Before holding the focus group you will need to translate the information sheet and consent form provided into your own language, ensuring the font size is suitable for older people who may find reading small print difficult. You may find it helpful to have two people facilitating each focus group, one to lead the discussion and one to make notes of the key points. As well as making notes, we would like you to record the session. After the session please can you translate the key points from the notes into English and send them to Dr Verina Waights (email: v.waights@open.ac.uk), along with an English translation of the transcript from the session. If this is not possible, please can you send a copy of the transcript in your own language or a copy of the recordings themselves.

The session

Firstly introduce yourselves, outline the DISCOVER project and the purpose of the focus group and ensure each person completes a consent form. Ask each person to briefly (in 5 minutes) introduce themselves and their caring role before opening the discussion up to cover digital skills etc. Use the discussion prompts below to facilitate the discussion and draw out participants' views concerning their need for digital skills and the value of technologies in helping them in their caring roles and to improve their quality of life. When examples of likely answers are given in bracket under a question, you do not need to go through this list but after they have suggested answers you could proffer some of the examples to act as an aide memoire. You don't need to follow the prompts rigidly as much of the information may arise naturally through the discussion. You may find it helpful to take along a smart phone or a tablet computer to illustrate your discussion about the kinds of technologies that are available. About 30 minutes before the end of the session, check the discussion prompts to make sure that you have covered the majority of the points given below. The data generated will be used to identify the carers' needs for developing their digital and caring skills and knowledge.

Discussion Prompts

Caring roles

- Can you tell us a little about yourself and your caring role?
  (How long you have been a carer, who you care for, what you do as a carer)

- What everyday challenges do you face as a carer?

- Do you have any support to help you as a carer?

Technologies

- What technology do you have access to?
  (PC, tablet, smart phone, digital TV, wii, Xbox)

- How often do you use these technologies yourself?

(Daily, weekly, monthly, 3/4 times a year, once a yr)

- What do you use?
  (Word, Excel, digital camera software, Internet banking, shopping, booking holidays, emailing, making appointments, games machines, BBC iplayer)

- Do you currently use any digital Technologies to support your caring role?

Supporting Carers

- How do you think technology could help to support you?

- What digital skills do you think would help you to get the best use from technology?

- Do you have any concerns about using technology?

- What type of training would you want to learn new digital skills?

- Would you find it helpful to learn more about the health condition of the person you care for? If so, which conditions could be helpful?
  (Diabetes, dementia, heart disease, stroke, COPD)

- Would you like to gain/improve your employability skills?
  (CV writing, interview techniques)

- Would you like to be part of a group of carers who meet online?

- How do you currently find out about services available to you?
- (AgeUK, Library, internet search)

Supporting the people who are cared for

- How do you think technology could help the person you care for?
  (Internet shopping or banking emails, booking appointments, learning more about health and Tele-care)

- What skills would you need to help the people you care for to use technology?

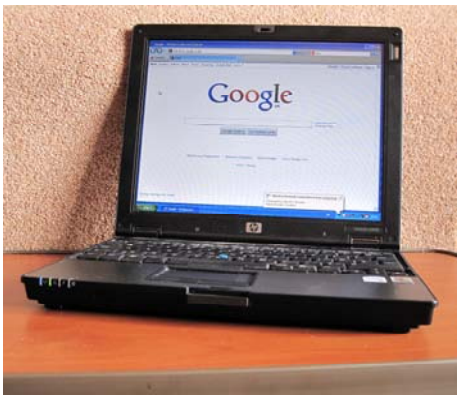
- What skills would those that you care for need to use technology by themselves?

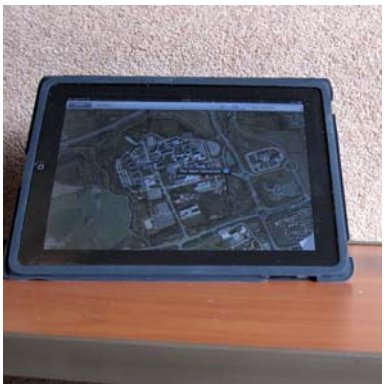
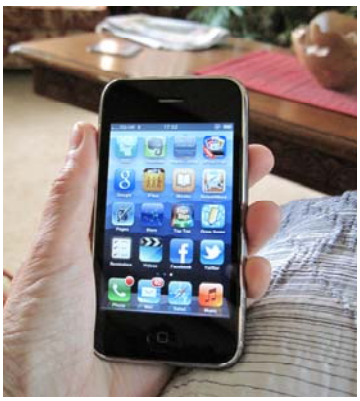
Participant Information Sheet

Purpose of the study

Due to an increasingly ageing population, there is an increasing demand for quality care across Europe. However, public services are unlikely to meet all of this demand, resulting in family members being expected to take on more and more care tasks and make more demands on stretched professional health care workers. Currently, over a 100 million people in Europe care for a family member, partner, relative or friend and this figure is expected to rise sharply.

This pan-European project, based in Greece, Spain, the Netherlands and the UK, is focused upon improving the quality of life of carers and the older people they care for through digital technologies, such as computers and mobile phones, ultimately helping to reduce their social isolation.



DISCOVER will enable carers to access the information they need, when they need it and foster a shared learning environment for communities of carers to share experiences, knowledge, challenges and questions.

DISCOVER aims to

- to improve carers' skills in using computers and other technologies to help them to find information, write letters, acquire new knowledge and skills, and meet other carers
- enable carers to pass on these skills to the older people they care for
- provide opportunities for both carers and older people to learn these skills together.

Procedures

Focus groups are being undertaken to identify what carers would need to develop or enhance their computing, caring, and care management skills.

The focus group will consist of no more than ten current or former carers, and will last approximately two and a half hours. During the focus group session you will be asked about your experiences as a carer, your use of digital technologies and your views about the value of digital technologies in assisting you in your caring role or for future employment. The discussion will be tape-recorded and securely stored on a password-protected computer. You will be able to leave the session at any point.

With your permission, we may take photographs and video recordings and use them in presentations, journal articles and media including the project website.

Potential Benefits

Taking part in the study will not benefit you directly. However, what you say will inform the development of appropriate learning materials, which will be trialled by other carers who agree to participate in the main phase of the project.

Potential Risks

There are no particular risks associated with this project. However if you do not wish to answer any questions posed during the session or be photographed or videoed you can say so. You can withdraw from the study at any point (please see Right to Withdraw below).

Storage of Data

Focus group information, including photographs and video recordings, will be stored securely on a computer that is password protected. Only partners will be able to access the computer and the information will not be discussed with anybody outside of the project partnership. Your name will not be on any of the information, therefore you will remain anonymous. Consent forms will be stored separately from the focus group information. Paper copies will be kept in a locked cabinet.

Your name will not appear in any written report and any direct quotations that may be used in reporting the results of the project will be presented in a way that you will not be identified.

Right to Withdraw

Your participation is voluntary and you may withdraw from the project at any point for any reason. If you withdraw following the focus group meeting you may request that the data you have contributed is destroyed.

Questions

If you have any questions concerning the project please feel free to contact [insert contact name] at any point. If at any point you wish to discuss any aspects of the project with somebody other than [insert contact name] you can contact the following person:

[delete contacts outside your country]

Greece

Prof. Panagiotis D. Bamidis

bamidis@med.auth.gr

Ireland

Andrew McFarlane
andrew.macfarlane@casala.ie proyectos1@intras.es

Spain

Victoria de Vena
victoriadevena@hotmail.com

The Netherlands

Roul Wessels
roulwessels@astracom.Nl

The above person can also be contacted in writing via the address at the bottom of this information sheet.

The study has been approved on ethical grounds by the [insert your country's Ethics Committees as appropriate].

If you would like a copy of the results of the study please contact [insert contact name].

[insert contact name]
Email: [insert contact email address]
Tel: [insert contact telephone number]
Address: [insert contact address]

Participant Consent Form

Please initial box

1. I confirm that I have read and understand the information sheet for the above project. I have had the opportunity to consider the information and ask questions, and I have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my care or legal rights being affected. ☐
3. I understand the conditions under which personal information collected in this project will be confidential, anonymous and protected. ☐
4. I give permission for information, including the use of quotations, collected during the focus group meetings, audio or video recordings, to be used in any presentation of the findings with the understanding that my anonymity will be assured, unless I waive my anonymity in writing. ☐
5. I give permission for photographs and video recordings taken during the focus group meetings to be used in any presentation of the project, including the project website. ☐
6. I agree to take part in the above study. ☐
7. I agree/ do not agree (please delete one) for any video recordings to be placed on social media sites such as YouTube.

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Name of participant	Date	Signature
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Name of person taking consent	Date	Signature