



## D2.6 - ETHICAL GUIDELINES

---

### Good practices in the project

<b>Project acronym:</b>	POSTHCARD
<b>AAL JP project number:</b>	AAL-CALL-2017-045
<b>Deliverable Id:</b>	
<b>Deliverable Name:</b>	
<b>Status:</b>	Draft/final
<b>Dissemination Level :</b>	Public
<b>Due date of deliverable:</b>	M12
<b>Actual submission date:</b>	30-12-2018
<b>Author(s):</b>	
<b>Lead partner for this deliverable:</b>	HUG
<b>Contributing partners:</b>	

# Contents

---

Version history	2
Project partners	3
Document information	3
Purpose of the document	3
Global concept of POSTHCARD	3
Responsability	3
Privacy and ethics in general	4
Fundamental and human rights	4
What does this mean for POSTHCARD?	5
Right and ethics in research activities POSTHCARD	6
Ethical approval	6
Informed consent	6
Debriefing	6
Giving consent	7
Conducting research	8
Additional guidelines for specific POSTHCARD research activities	8
Technology and privacy	11
Data storage management POSTHCARD	11
Cookies	11
Implementation of ethics during product development	13
General guidelines	13
References	16
Appendix A: Informed consent focus group phase 1	17
Appendix B: Informed consent focus Group wave 2	21
Appendix C: Informed Consent co-creation sessions Phase 1	25
<b>Check the boxes</b>	<b>Error! Bookmark not defined.</b>

## Version history

---

Version	Authors	Date	Description
0.1	F.Ehrler	23-06-2018	


## Project partners

Partner #	name	abbreviation	country
1	University Hospital of Geneva	<b>HUG</b>	Switzerland
2	University of Geneva	<b>UNIGE</b>	Switzerland
3	Father Equipment	<b>FTH</b>	Romania
4	ConnectedCare	<b>CCARE</b>	Netherlands
5	University of Twente	<b>TWE</b>	Netherlands
6	Alzheimer Nederland	<b>AZN</b>	Netherlands
7	Vilans	<b>VIL</b>	Netherlands
8	Conectar	<b>CON</b>	Belgium

## Document information

### Purpose of the document

The purpose of this deliverable is to evaluate and validate the POSTHCARD project in relation to legal aspects of introducing this innovative platform in people's lives. Therefore, this document mainly describes the ethics that have to be taken into account throughout the entire project. This includes research activities with human subjects to ensure the safeguard of their ethical and privacy rights, as well as privacy regulation concerning data. The report should be considered as a first attempt to draw up the lines, borders, challenges, possibilities, and barriers that legal aspects are and will be for a project like this. The project should use the report both as a reference in the project and as a source for input and discussions around these issues. As more ethical issues may arise during the development of the product, this report will be updated throughout the project duration.

### Global concept of POSTHCARD

POSTHCARD focus on training caregivers to deal with Alzheimer people in order to relieve burden associated to care. The training rely on a innovative simulation allowing user to practice daily situation

## Responsability

HUG is the organisation responsible for this deliverable. XXXX is a contributor and reviewer of the document.

# Privacy and ethics in general

---

## Fundamental and human rights

Even with or without the presence of technology, European citizens have fundamental rights according to European laws. These fundamental and human rights that are related to the POSTHCARD project must be guaranteed at the European level for all its citizens.

### **Article 8 of the European Convention on Human Rights (Council of Europe, 2010) “Right to respect for private and family life**

1. Everyone has the right to respect for his private and family life, his home and his correspondence.
2. There shall be no interference by any authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.”

### **Article 7 of the European Union Charter of Fundamental Rights (Council of Europe, 2010) “Respect for private and family life**

1. Everyone has the right to respect for his or her private and family life, home and communications.”

### **Article 8 of the European Union Charter of Fundamental Rights (European Communities, 2000) “Protection of personal data**

1. Everyone has the right to the protection of personal data concerning him or her.
2. Such data must be processed fairly for specified purposes and on the basis of the consent of the person concerned or some other legitimate basis laid down by law. Everyone has the right of access to data which has been collected concerning him or her, and the right to have it rectified.
3. Compliance with these rules shall be subject to control by an independent authority”

### **Article 16 of the Lisbon Treaty (European Union, 2008)**

1. “Everyone has the right to the protection of personal data concerning them.
2. The European Parliament and the Council, acting in accordance with the ordinary legislative procedure, shall lay down the rules relating to the protection of individuals with regard to the processing of personal data by Union institutions, bodies, offices and agencies, and by the Member States when carrying out activities which fall within the scope of Union law, and the rules relating to the free movement of such data. Compliance with these rules shall be subject to the control of independent authorities. “

3. The rules adopted on the basis of this Article shall be without prejudice to the specific rules laid down in Article 39 of the Treaty on European Union.

A number of reasons for the protection of privacy can be distinguished. One is to give people power to control the publication and distribution of information about themselves, another can be to be able to protect themselves from unauthorized access to information about themselves they regard as private.

### What does this mean for POSTHCARD?

As POSTHCARD will offer a personalized experience, personal information and usage data will be required in order for the platform to work efficiently. Moreover, several research activities requires the collection of personal information from participants in order to identify user requirement and to test the effectiveness of the platform (WP 2&4). Chapter 3 will describe how the POSTHCARD project will deal with rights and ethics in research activities being carried out, while chapter 4 will reflect on technology and privacy in relation to the product being developed.

# Right and ethics in research activities POSTHCARD

---

The development of new technology is generally accompanied with research activities that included human subject sharing their thoughts and experiences. Within the POSTHCARD project, several research methods will be used to determine (WP2) and validate (WP4) the direction of the POSTHCARD project. To protect human subject in these research activities, each activity has to take into account several ethical aspects and human subjects' rights. Below regulations concerning ethical issue management in general, as well as within POSTHCARD, will be described.

## Ethical approval

Some research activities that include participation of human subjects will have to request for ethical approval from a set ethical committee. Especially in case of a medical intervention. As POSTHCARD has no focus on any kind of medical intervention no medical ethical approval will be needed. However, each trial site has to check whether any other kind of ethical approval will be required, as this might depend on national regulations or regulations from partners' organisation.

## Informed consent

Before human subjects – in research also referred to as participants – can participate in any kind of research, their consent to take part in the research activity has to be given. Participants giving their consent is needed in any type of research being performed, as it includes that participants are agreeing with the research activities being performed, but also with its possible risk and benefits. Giving consent includes several steps, namely debriefing possible participants about the study and about their rights as a participants, but also giving consent.

## Debriefing

Before a possible participant can decide to take part in any research activity it has to be clearly informed about the research activities being performed, its rights and what happens with personal information being collected. It is not important how the information is given to the user, but the person asking for consent has a clear responsibility to give information and to make sure that the consenting party has understood the information given. There are usually no formal requirements for consent. It can be written, oral, presumed, etc. In research projects with human objects, it is highly recommended to obtain written consent.

Information that needs to be explained include:

- Goals of the study
- Research procedure (what will happen)
- Participants inclusion (where are people sampled for)
- Participants' rights
- Possible risk
- Possible benefits
- Participants' rights
- Data management (what information is being collected, what will happen to this information)
- Contact person when having questions

## Participants' rights

A human subject involved in research activities in research is referred to as a participant. While being involved in research, participants have many rights:

- **Voluntary.** Being involved in any kind of research activity has to be voluntary, by no means can people be forced to be involved with any research activity. Moreover, it is fundamental for a valid consent that it is given freely and without any pressure.
- **Freedom to withdraw.** The participants has the freedom to withdraw from the research activity at any moment without giving any explanation or any drawbacks.
- **Limited actions of researcher.** The performing researchers' actions are limited to the extent of the consent both in time and space, meaning no other activities than mentioned in the informed consent can be conducted without asking for the participants' consent.

## Data management

As the goal of any kind of research is to learn from participants, (personal) information will be collected. This information can be of any kind, for example audio recording, video recordings, photographs, notes, answers to questionnaires, physiological data, or drawings. One way or the other, personal information is being collected, and there are regulations about how to treat this information.

- **Anonymization.** Results being collected must be reported anonymously so that no personal information can be directed to them directly. This includes that either the usage of fictive names or the use of participant numbers when reporting information, and that faces of people are blurred when sharing pictures for publications.
- **Access.** Information that contains any kind of personal data should be kept confidential and not shared outside the group in charge for analysing the data and obtaining the data to prevent abuse of the information. This includes that personal information should be kept behind a lock (digital or physical).

Besides the above mentioned regulations, participants need to be informed before giving their consent about what will happen to their data and what kind of data will be collected. The information that should be given includes:

- What kind of data will be recorded, stored and what is the reason accessing this data?
- Who has access to the data?
- Who owns the data?
- Is the data connected to other information?
- Will the data possibly be commercially exploited?
- Length of storage?
- Privacy protection (anonymization of personal information and keeping behind a lock)

## Giving consent

After a clear debriefing participants can decide whether or not to give their consent to take part in the research activity. It is a general rule that the consenting person must understand what he/she is giving consent to. This means that a person, mentally incapable of understanding this, cannot give valid consent. Such incapability can be temporary, but especially for elderly people there are examples of persons without consenting power due to dementia and similar diseases. In such cases a guarding should be appointed that can assess and give consent on behalf of the



patient. Within POSTHCARD it is very unlikely that some patient-users are incapable of understanding what they are asked to give consent to, as no people with health constraints are specifically targeted.

Besides the participant giving his consent, the researcher performing the activities also has to sign the informed consent so that what the participant has given consent to will be respected by the performing researcher. When the participant has given his consent, the participant receives a copy of the informed consent. As an iterative approach will be used, participants might be involved in the same research activity more than once, in which the focus of the activity can change. To avoid that the participant has to completely read the same informed consent for each activity, the performing researcher has to take into account using one informed consent, in which participants will only have to place a signature for the session they were participating. **The informed consent being used during the research activities can be found in Appendix**

## Conducting research

When the actual research activities are being performed, there are also regulations and suggestions on how to perform these activities in general research activities.

### Dealing with participants

Any participants should be given respect, this also includes their opinion. There are by no means no right or wrong answers, as any opinion is one to be valued. Participants should therefore be given enough opportunities to express their own opinion, this includes allowing a participant to finish his sentences, but also to not enforce the researchers' opinion to the participant.

### Everybody should be able to join

There could be several factors that might hinder participation in any research activity, however anybody that fits the inclusion criteria should be able to join. For example, a person who is not very mobile could be picked up by taxi service or by someone involved in the project.

### Value the voluntary participation

People are giving their spare time to participate in a research activity. Although people could find these activities enjoyable, there must be something else in exchange for their valuable time. First of all, joining a research activity must not cost the participant any money. Any cost related to traveling for the research activity must be compensated (e.g. train tickets, taxi services, kilometre allowance). Although not mandatory, it is also advised to give the participants something extra for their effort, especially when people can be approached multiple times for research activities. For example, give a gift certificate and provide something nice to eat and drink, longer sessions could even include lunch.

## Additional guidelines for specific POSTHCARD research activities

Several research activities are being performed, which each might have their own additional guidelines according to ethics. Within POSTHCARD, these will be a difference in research activities performed at a predefined research facility or at people's own homes.

## Predefined research facility

### Questionnaire

Several research activities included the usage of a questionnaire, as this helped to ask for general information, but also about more privacy related issues. In order to allow to link the input from the questionnaire to the other research activities being performed, the participant code can be mentioned on the questionnaire. Mentioning the participant name on these questionnaires is not recommended, in relation to privacy.

### Focus group

A focus group is basically a group interview, with at least one moderator and one observant. Compared to a one-on-one interview there are a few rules to take into account:

- **Time.** Maximum duration for focus groups will be two hours (including a break)
- **Privacy sensitive topics.** Not all topics allow for a *group conversation*, as people might not want to share this into a group. This might include for example income, private relationships, and healthcare conditions. One-on-one conversation do allow for more sensitive topics. Some one-on-one interviews were conducted, as these persons were unavailable on the focus group dates, or lived too far away from the session location. This offered that personal question could be asked to gain insight depth (e.g. why do people make changes, were they financially stimulated, are people lonely)
- **Homogeneous group.** Within a group of people talking about their personal experiences people must feel comfortable talking about the topic, and not have the feeling that they are being judged by others of the group. To achieve this, groups must be as homogenous as possible, what is seen as homogenous depends on the context of the research and the group. Within POSTHCARD this was defines as people around the retirement age. Within POSTHCARD factors that might harm the homogeneity of the group include: level of education, level of digital experience.
- **Familiarity between participants.** People within a focus group should not know each other, as this might create an unbalanced dynamic in a group discussion.
- **Non-judgemental moderator.** The moderator acts as a mediator, helping the participants express their views without expressing its views. This also includes non-verbal communication, such as nodding. Moreover, this also includes that if the moderator does not agree with the opinion from the participants, he or she should respect the participants' opinion.
- **Equal opportunities to talk.** All participants should have the option to express themselves. This might include that talkative participants might have to be reduced to talk, while quite types might have to be stimulated to talk. When a talkative person dominates the conversation a moderator for example could say "That is very interesting, what do the others think about this?". It is suggested to prevent as much as possible to directly ask a person how they feel, as quiet types might feel uncomfortable in this situation.

### User Profiling

User profiles – also referred to as personas- are fictive representations of the target group that help the design process. This means that they are a realistic portrait of a user that helps focus on specific user needs rather than market tendencies. However, these personas will not represent a participant from any user activity directly. **Figure 1 shows an example of one of the user profiles within POSTHCARD. More information about these profiles can be found in D end user requirements.** These personas will be used to for the ideation of the concept, but also for further

design choices, as they represent the target group. It is therefore important that these personas reflect realistic persons to prevent a misfit with the product outcome. However, personas never are a direct copy of a singular person of the research activities (e.g. focus groups) being performed).

Figure 1: *Example of one of the user profiles within POSTHCARD.*

### Co-creation

Co-creation means, for a company, developing products or services in active collaboration with its customers in a sustainable way. There are a few rules to take into account like in focus group (Time, Privacy sensitive topics, Homogeneous group, Familiarity between participants, Non-judgemental moderator, Equal opportunities to talk). The participants must correspond to the typical profile of the end users, because we have to be closer to the people who will use the final application. The documents that must be completed by our participants do not contain direct references to them. They must be anonymous. The link between participants and documents collected during focus group or co-creation sessions can be made through an identification number that will be given to each participant. When a participant speaks, the interviewer shouldn't interrupt him.

### What users think about the trust and the profile?

The co-creation sessions also allow discussing about the trustworthiness of the platform. If the users say that they aren't at ease with websites that ask for a lot of information in the profile (picture, name, and phone), for fear that the information will be misused. They also don't like when people share too much about themselves (they gave the example of facebook). For them, it's important that we advise them on the security of the platform and that the information given on the profile is optional and/or hidden for other users.

### Prototyping with the end-users

During co-creation, prototypes are created with potential end-users to identify concepts that appeal to them and match their needs.

Figure 2: *Example of a co-creation session conducted for the POSTHCARD project*

### Research at people's own homes

Researches being performed at people's own homes are also referred to as field trials. Compared to non-field trials there are several points that should be taken into account:

- *Provide services and products for the test.* Everybody who fits the inclusion criteria should be able to join the field trial. In case certain services (e.g. internet connection) or product (e.g. smartphone, tablet) are needed to perform the test, but the participant lacks any of these, these products or services should be provided to the participants for at least the duration of the test.
- *Insurance.* During any test it can happen that something breaks, in these cases insurances must cover this.

## Technology and privacy

---

The role of technology within peoples' life is increasing over the years. However, with more technology being available and having a more important role than for dozens of years ago, it is important to look at privacy and ethics of this technology entering peoples' life.

### Data storage management POSTHCARD

Since POSTHCARD aims at offering a very personalized experience it is likely that it will collect a lot of personal information can be available about the user and their relatives. Although the exact boundaries of POSTHCARD are not yet defined, as this will be shaped more along the project, personal information could for example include their location, profile, preferences, and medical condition from the relative. The big question is how to secure the citizen privacy rights when introducing her or him to technologies.

### Cookies

Within POSTHCARD, it is very likely that cookies will be present, which is the case with many platforms. Cookies are "small files, typically of letters and numbers, downloaded on to a device when the user accesses certain websites. Cookies allow a website to recognise a user's device" (Information Commissioner's Office, 2012). There are different type of cookies, which each a different level of knowing privacy related content of the user. The type of cookie being used within POSTHCARD has to be considered.

#### Session cookie

Session cookies allows websites to link the actions of a user during a browser session. They may be used for a variety of purposes such as remembering what a user has put in their shopping basket as they browse around a site. They could also be used for security when a user is accessing internet banking or to facilitate use of webmail. These session cookies expire after a browser session so would not be stored on the longer term. For this reason, session cookies may sometimes be considered less privacy intrusive than persistent cookies.

#### Persistent cookies

Persistent cookies are stored on a users' device in between browser sessions which allows the preferences or actions of the user across a site (or in some cases across different websites) to be remembered. Persistent cookies may be used for a variety of purposes, including remembering users' preferences and choices when using a site or to target advertising.

Since every user will have the opportunity to choose interests in their account, theses preferences may be stored by cookies in order to personalize activities proposed to the user.

#### First and third party cookies

Whether a cookie is 'first' or 'third' party refers to the website or domain placing the cookie. First party cookies in basic terms are cookies set by a website visited by the user - the website displayed in the URL window. Third party cookies are cookies that are set by a domain other than the one being visited by the user. If a user visits a website and a separate company sets a cookie through that website this would be a third party cookie.

At the moment, it is unclear if third party cookies will be used for advertising, this will depend on the business model.

## Consent for using cookies

It is not allowed to use cookies while the user does not know about the presence of these cookies. Therefore, any website using cookies must “provide clear information about the cookies but also to obtain consent from users or subscribers to store a cookie on their device. This information includes telling people about the presence of cookies, explain what the cookies are doing, and obtain their consent to store a cookie on their device.” (Information Commissioner’s Office, 2012).

This consent can be given in two manners. First possibility according to Information Commissioner’s office (2012) is that consent can be obtained from the subscriber or user. The subscriber includes the person who pays the bill for the use of the line. The user is the person using the computer or other device to access a website. The second possibility they give is to rely on the browser for obtaining the consent of the user. More specific, obtaining consent by browser setting is allowed browser if they can be used in a way that allows the subscriber to indicate their agreement to cookies being set. In other words, if the user visits a website, the website can identify that their browser is set up to allow cookies of types A, B and C but not of type D and as a result can be confident that in setting A, B and C they have the users consent to do so. They would not set cookie D.

According to Information Commissioner’s office (2012), exceptions in relation to the requirement of providing information about cookies and obtain consent for using this cookie are present. First exception includes cookies “for the sole purpose of carrying out the transmission of a communication over an electronic communications network”. Second exception includes cookies “where such storage or access is strictly necessary for the provision of an information society service requested by the subscriber or user.”

As the exception principle is not 100% definable clearly the ICO provides examples:

### Activities likely to fall within the exception

- A cookie used to remember the goods a user wishes to buy when they proceed to the checkout or add goods to their shopping basket
- Certain cookies providing security that is essential to comply with the security requirements of the seventh data protection principle for an activity the user has requested – for example in connection with online banking services
- Some cookies help ensure that the content of your page loads quickly and effectively by distributing the workload across numerous computers.

### Activities unlikely to fall within the exception

- Cookies used for analytical purposes to count the number of unique visits to a website for example
- First and third party advertising cookies
- Cookies used to recognise a user when they return to a website so that the greeting they receive can be tailored.

## Implementation of ethics during product development

When developing a product, especially a new product, ethics is not something you take into account once. Instead, taking ethics into account during development is a process rather than checking whether it is aligned with a list of requirements. During development new issues might

arise. In order to make sure that ethics are taken into account during development several talks with the technical team about ethics have to be arranged, but also ethics can be a reoccurring event on the agenda of digital and face to face meeting with the consortium partners.

## General guidelines

Besides the fundamental rights there are no general European guidelines set on how to develop and implement technology in ways that it ensures and secures the right to privacy and ethics. Despite this, several countries have their own recommendation regarding this issue which in general are much alike.

### *Legislation and recommendation Norwegian Data Protection Authority*

#### **1. Choose the least radical solution**

When choosing between different technological solutions, the solution that is the least radical should be preferred. Choose of solutions should be user driven and adapted to user needs.

In relation to POSTHCARD, the platform will be developed according to the needs of potential users gathered during focus groups and co-creation sessions.

#### **2. Limit the amount of data stored**

The amount of stored data as part of a given service should be limited as much as possible. Unnecessary data shall not be stored at all.

Within POSTHCARD, only data requiring persistent backup will be stored.

#### **3. Choose real-time solutions when possible**

Usually, real-time solutions are less invasive than solutions that stores information about the user. For example, one should not store information about an older persons movements if the purpose simply is to be able to find her if she goes missing.

Within POSTHCARD, only the necessary data will be stored.

#### **4. Local storage if possible**

Data or information that will only be used locally shall be stored locally and shall be deleted after use. One example of such data is sensor information.

Within POSTHCARD, data about the current session will be stored locally and deleted after use.

#### **5. Give the user control**

In general, technology that is based on the actions from the user is less invasive than technology that is controlled by “someone” from the outside.

Within POSTHCARD

- Option to choose what information will be shared with others.

#### **6. Delete data**

Technological solutions should include automated functions for deletion of information when information is no longer in use.

Within POSTHCARD, the user will be able to destroy his profile permanently without leaving any traces.

## 7. Limited access

Access to personal information shall be limited to as few as possible and only to those that have a professional need for the information. Solutions where a number of people have access must have in place systems and routines for access control as well as systematic checking of log-information.

Within POSTHCARD, data will be only accessible to the user itself

## 8. User access to information

Solutions should be developed in a way that it is fairly easy for the user to gain access to his or her own information in the information systems. This shall include information about other persons' access to the information (log-information).

Within POSTHCARD,.

## 9. Encryption

Personal information shall be encrypted at least when they are used, for example by transfer of information, outside secure information systems.

.

## 10. Anonymize data

If there is a need for storing of data for statistical or quality assurance purposes, the data must be anonymized.

Within POSTHCARD, it might be recorded how users browse on the POSTHCARD platform.

### *Privacy by Design (PbD)*

Besides the recommendations on data protection, there are other privacy principles that might be worth taken into consideration. A former Information and Privacy Commissioner of Ontario in Canada developed the PbD framework into a basis of 7 so-called Foundation principles (Cavoukian, 2011):

**“Proactive not Reactive; Preventative not Remedial.** Do not to wait for privacy risks to materialize, nor offer remedies for resolving privacy infractions once they have occurred – aims to prevent them from occurring.

**Privacy as the Default Setting, without any actions required from the user.** Personal data automatically being protected in any given IT system or business practice will ensure a maximum degree of privacy. For example, if an individual does nothing, their privacy still remains intact by default in the system, no action is required on the part of the individual to protect their privacy

**Privacy Embedded into Design, IT architecture, and business practices.** This will result in that privacy becomes an essential component of the core functionality being delivered, leading to that privacy is integral to the system without diminishing functionality.

**Full Functionality – Positive-Sum, not Zero-Sum.** Accommodate all legitimate interests and objectives in a positive-sum “win-win” manner, not through a dated, zero-sum approach, where unnecessary trade-offs are made.

### **End-to-End Security – Full Lifecycle Protection**

Privacy by Design, having been embedded into the system prior to the first element of information being collected, extends securely throughout the entire lifecycle of the data involved – strong security measures are essential to privacy, from start to finish. This ensures that all data are securely retained, and then securely destroyed at the end of the process, in a timely fashion. Thus, Privacy by Design ensures cradle to grave, secure lifecycle management of information, end-to-end.

### **Visibility and Transparency – Keep it Open**

Privacy by Design seeks to assure all stakeholders that whatever the business practice or technology involved, it is in fact, operating according to the stated promises and objectives, subject to independent verification. Its component parts and operations remain visible and transparent, to users and providers alike. Remember, trust but verify.

### **Respect for User Privacy – Keep it User-Centric**

Above all, Privacy by Design requires architects and operators to keep the interests of the individual uppermost by offering such measures as strong privacy defaults, appropriate notice, and empowering user-friendly options. Keep it user-centric.”



## References

---

Cavoukian, A. (2011). Privacy by Design: the 7 foundational principles. Retrieved from <https://www.ipc.on.ca/wp-content/uploads/Resources/7foundationalprinciples.pdf>

Council of Europe. (2010). European Convention on Human Rights. European Court of Human Rights. Retrieved from [http://www.echr.coe.int/Documents/Convention\\_ENG.pdf](http://www.echr.coe.int/Documents/Convention_ENG.pdf)

European Communities. (2000). CHARTER OF FUNDAMENTAL RIGHTS OF THE EUROPEAN UNION. *Official Journal of the European Communities*, 100(364/01). Retrieved from [http://www.europarl.europa.eu/charter/pdf/text\\_en.pdf](http://www.europarl.europa.eu/charter/pdf/text_en.pdf)

European Union. (2008). Consolidated versions of the treaty on European Union and the treaty on the functioning of the European Union C 115/01). Official Journal of the European Union.

Information Commissioner's Office. (2012). Guidance on the rules on use of cookies and similar technologies. Privacy and Electronic Communications Regulations. Retrieved from [https://ico.org.uk/media/for-organisations/documents/1545/cookies\\_guidance.pdf](https://ico.org.uk/media/for-organisations/documents/1545/cookies_guidance.pdf)

# Appendix A: Informed consent focus group phase 1

---

