LILY Project (AAL-2010-3-027)

D1.7 Ethical Issues and Legal Issues and Proposals on Legal and Ethical Issues (M36)

A Summary of Activities and New Issues

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1.   Introduction

The LILY project focuses on wellbeing services for self-serve supporting environments according to the needs in third age from the viewpoint of ICT, taking into account the whole human life-cycle. The primary target group is people over 55 years of age. Other target groups considered comprise health and social care giving personnel, family members, relatives and friends, local authorities, service providers, content suppliers, retailers and merchandisers. LILY solutions will be developed using industry-adopted and emerging technologies such as web 3.0 standards, including web services and semantic technologies, video technologies, touch-screens and a variety of end-user devices and interfaces. Co-operational models will be bases for creating value network's business models. LILY solutions will be developed based on three existing systems and piloted in two real-life environments. For the new user interfaces the project will pilot sensory environments using printed electronics.

LILY aims at putting the technology at the service of three dimensions of users: the single individual older persons, persons in direct contact with their professional care and social workers as well as family members, together with the institutions and private organizations paying and enabling services that are public sector, social security or insurance companies.

LILY prototypes the needed products and services. Pre-industrial prototypes of the products, validated in 2 pilot sites in Finland and France will be available at the end of the project. The expected benefits include for older persons: improved quality of life, independent living and decision-making. For carers: communication efficiency, increase cost-benefit standards. For the SMEs and service providers: advanced products demanded by users and a big market opportunity. As an outcome a set of business models are created which are easy to replicate at new sites.

The Deliverable 1.7 *Ethical Issues and Legal Issues and Proposals on Legal and Ethical Issues (M36): A Summary of Activities and New Issues* at hand summarizes the approach taken to ethics in the LILY project and reports about the additional ethical and legal issues that were identified and were observed and discussed among the partners in the course of the project. LILY has a strong commitment to ethics as a starting point. This is reflected in its values which include the improvement of the quality of life, autonomy, participation in social life, skills and employability through a transportable adapted home environment for self-served daily living activities.

2.   Ethics in the LILY Project

In preparing the LILY project, ethics was given a central role in the WP1 and a task and deliverable in WP4. It was anticipated that the user-centered approach to the proposed research and development work would require a robust framework for addressing research ethics throughout the project's trajectory.

The objective of the ethics-related tasks was to draft early on in the project an ethics guideline which would be continuously updated if/when necessary. The main features of the guidance document included:

- Identification of the key ethical and legal issues that need to be addressed throughout the project and in the project's ethics guideline;
- Identification of the major international documents and guidelines on ethics and establishing their relevance on the topic areas of the LILY project;
- Identification of national guidance documents, legislation and governance bodies in ethics that are relevant for the national LILY partners in implementing their work;
- Identification of other relevant guidance documents (for example professional codes of conduct; documents on principles of research ethics etc.) that will support the work of the LILY project;
- Drawing on the international documents and other guidance document, creating a code of conduct / guideline document for the purposes of the LILY project;
- Laying down the principles and a practice for an appropriate user participation, including recommendations for recruitment, methods, and timing of user involvement;
- Providing hands-on guidance for creating a process for informed consent and drafting of informed consent documents at the project's sites.

The focus on ethics was deliberately placed on the user involvement activities. Although the work can be described as anticipatory and proactive, the possibility to follow up on ethics and collect emerging ethical issues and observations with ethical relevance as they would arise, was embedded in the plan of the project. The project partners were encouraged to reflect on possible ethical issues throughout their work. All partners were involved in the ethics work.

In the WP1 and WP4, two separate ethics documents to guide the research and development work were written. These deliverables are:

- Deliverable D1.1/D1.2: Ethical and Legal State of the Art and User Involvement
- Deliverable D4.2: Project Ethics Policy

Based on a literature review of common frameworks used to address research ethics in other related fields and a close examination of examples of how ethical issues have been addressed in other, contexts similar to LILY, overview of the legal frameworks of the European Union and Finland and France, where the user involvement and piloting were to take place, the Deliverables D1.1/D1.2 and

D4.2 formed a comprehensive approach to encountering ethical issues in the trajectory of the project.

2.1 Comprehensive and process-based approach

A comprehensive approach to ethics was adopted in the LILY project from the outset. An ethics policy and a document on ethical and legal state of the art and user involvement were provided for the support of all partners, especially those collaborating with various end users. The ethics policy focuses on ethical principles in research, informed consent, and relevant national and EU legislation and policies. D1.1/1.2 addresses more closely user involvement in the LILY context.

The ethics guidance documents are based on commonly accepted principles of research ethics, backed up by a literature review and years of experience in ethics management in national and international R&D projects.

In order to help researchers and developers in their user involvement activities, a check list and reminders were provided with a focus on ethical aspects to take into account before, during, and after user involvement activities. References to legal frameworks, especially from the point of view of data protection, privacy, and relevant bodies governing research ethics, were included. The legal context addressed the EU level and the level of the national legislation in Austria, Finland, and France. The documents provide comprehensive support in planning strategies for data management, informed consent, and exit. The exit strategy is revisited in this document below.

In keeping ethics high on the agenda, the project partners were encouraged to keep track on any ethics issues that might arise during the project. In this way, a continuous, or, a process-based approach to identifying, addressing, and resolving ethics issues in the project was adopted in LILY. The partners raised the issues of ethical aspects of their own work in implementing new technologies in users' homes, the potential privacy issues related to semantic web, and the exit strategy with regard to the technologies used during the project as issues. An issue was also raised related to drop outs in the project. All these questions will be briefly discussed in what follows.

3.   Ethical dimensions in LILY

Although no genuinely new ethical issues could be identified in involving the users in the research, there were particular ethical questions that drew the project partners' attention. Some of these unfolded during the project and were not foreseen at the time when the ethics guidance deliverables were drafted. This is rather typical in projects in which the ethics guidance is to be provided early on in the project to ensure that all actors share the same framework on ethics and that there is sufficient guidance available for submissions for formal ethics clearance (which was not required at either site in LILY).

3.1 Ethical dimensions of one's own work: Recruitment and Facilitation

There were a number of ethical dimensions to be addressed in collaborating with the users. To start with, the process of recruitment is an important topic in involving older users in technology projects. The establishment of trust between potential participants and researchers has key importance in this case. The French example of collaborating closely with municipalities in contacting the users proved a successful strategy. In the French case, the contact was initiated by the municipality and only then the research team and service providers entered the picture. Due to the fact that the research team was recommended by a trusted body, it was easier to access participants. The research team comprised specially trained facilitators who were engaged in the implementation of the new systems in the homes of the older people. The facilitators continued to keep in close contact with the participants.

Despite a well-defined recruitment strategy and the active engagement of the facilitators, some participants withdrew from the project. A major reason for drop-outs was the relatively slow pace at which it was possible to arrange Internet connections to some users. This remains to be an issue in some rural areas of France.

The engagement of facilitators deserves some attention also from the point of view of ethics. In setting up the user collaboration, it was noted that the kind of work that is required by those setting up an ICT-based service in the home of an older person requires many skills, including empathy skills, commitment and sensitivity.

In the French case it could be seen that the facilitators of the service not only took care of the implementation of the system and training of the older users of the system but they also acted as general support persons for the service users. They kept in close contact with the service users and often occupied the position of a person of trust in their lives.

There are two observations to be made about the experience of the French facilitators. First, the implementation of a new technological system in the home of an older person requires much personal contact and commitment and many skills beyond what could be anticipated at first. The successful adoption and continued use of a system is the result of much personal contact. The second observation is that the work can be emotionally taxing for the facilitators. They get to know

their clients on a personal level. The clients share their joys and sorrows with the facilitators. The work is then often closer to social work than to IT implementation.

The French partners' example of engaging well-trained facilitators to bring new technology into the homes of older users and keeping the system running shows that frequent and regular personal contact is necessary for successful and continued use.

3.2 New technology and ethical and legal questions: privacy and data protection

Some of the new technologies proposed as part of the care and support for older people in the LILY project raise ethical issues. The two issues raised by developers dealt with privacy aspects of semantic web and the use of RFID to help track carers' tasks. The risk to privacy by use of linked data environments a well-known topic especially in the semantic web community[1].

The privacy issues in the case of LILY are relevant especially because the users may not be aware of how to best protect their privacy and they will be using a system that they are likely to trust. In this case, the developers and service providers would seem to have a particularly strong responsibility to ensure protection of privacy of their clients. Moreover, the intended user group is one that will be using services that may expose their health and care related needs; the data that must be protected can be considered sensitive. This means again a greater responsibility to protect the data from becoming available to third parties.

The revision of the European Union's current Data Protection Directive 95/46/EU will place new requirements on services provided on the web. In particular, it will strengthen the so-called right to be forgotten to help people better manage data protection risks online. This means that when individuals no longer want their data to be processed and there are no legitimate grounds for retaining it, the data will be deleted. In fact, the ruling on the "Right to be Forgotten" issued by the European Court of Justice on 13 May 2014 already now means more stringent obligations concerning those who collect data. The right to be forgotten means that people can request web companies to delete personal data from their servers.

Other changes foreseen through the planned Data Protection Regulation have to do with consent and the increasing responsibilities of those who process data. Individuals must be asked for their explicit consent when consent is required for certain types of data processing.

In addition, the principles of 'privacy by default' and 'privacy by design' have been introduced to ensure that individuals are informed in an easily understandable way about how their data will be processed.

Some authors claim that the implications of the right to be forgotten have mostly interested the legal profession and been overlooked by technologists[2] It is essential for projects such as LILY that the system that is developed is embedded in the relevant and correct legal basis. The partners have anticipated in their discussions the new requirements and their potential effect on the LILY solutions.

The LILY partners are aware of the developments with regard to the reform the current Data Protection Directive and will implement in their future work the requirements of the reformed Data Protection Regulation which is expected to be finalized in 2015.

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[1] See, for example, A. Alotsibi. "Computer Ethics in the Semantic Web Age." IJACSA, Vol. 5, No. 7, 2014.

[2] See, for example, K. O'Hara. Can Semantic Web Technology Help Implement a Right to Be Forgotten. *Computers and Law*, 22, (6). Available at: http://eprints.soton.ac.uk/273096/

In addition the privacy issues surrounding the semantic web, the LILY project has encountered the ethical issues of Radio-frequency identification (RFID) technology as part of care services. The idea of using RFID technology to track the tasks fulfilled by care personnel in a client's household were explored. Such tracking could be useful as it would enable the quick identification of the tasks completed. Many professional care workers are already now equipped with some hand-held devices to for their clients and the particular tasks they are expected to complete. An RFID-based tracking system might not bring any significant changes to the current ways of working. Nevertheless, such systems would need to be carefully assessed by their potential users.

The trial use of the RFID technology in care provision in Finland will continue beyond the lifetime of the LILY project.

3.3 Wide notion of exit strategy in LILY: the meaning of (im)material interventions

It is widely known that no participant in a technology research and development project should be subject to any risk of physical harm (at least beyond risk of minimal harm). The risk of harm must be addressed throughout the trajectory of the participation, including the ending of the participation.

One of the tasks with regard to ethics is to ensure that the participating users may become dependent on the system during the trial time. It is thus important to proactively address the fact that the tested systems may not be (are likely not to be) available on the market for the users to benefit from at the end of the project. This information needs to be provided in conjunction with the informed consent process prior to the participation. The project team is responsible for ensuring that the users will not be left worse off after the trial use than prior to the participation. Also the French users can keep their equipment in future use. The costs of future use will be the responsibility of the users.

Because AAL projects often offer participants enjoyable experiences as test users, new skills using new technologies, even experiences of being empowered or enabled in new ways, the notion of an exit strategy has received much attention. This is also in the case of the LILY project. An exit strategy was formulated early on. As a result, the participants in the LILY trials were able to keep the systems they had in use (tablets). A follow-up period of 6 months will be applied at the Finnish site after which the users will be contacted for their feedback. This corresponds with a standard and material approach to exit strategy in the AAL context.

In addition to the approach to exit strategy, focusing on potential harms of removing equipment from users, the LILY project explored that there may be a need to adopt a wider notion of harm, including those of social, financial, and psychological harms as part of a sustainable exit strategy. The LILY perspective then expanded on the mainstream view and suggested a more comprehensive approach to exit strategies, taking into account multiple layers. These layers include an interpretation of intervention as having material and immaterial dimensions. The approach taken, and presented at the AAL Forum in Eindhoven 2012[3], argued for a need of an increased awareness of the immaterial dimensions of interventions and exit strategies in particular as a part of responsible post-project management.

In the LILY view the material interpretation of a technology intervention was described as follows:

> *The material interpretation of a technology intervention focuses on the tangible aspects of the system that are introduced to a participant's sphere of life. Following this interpretation the scope of a responsible exit strategy would center on the effects of the installation of a system in a home, its use, and removal. Various financial aspects, such as costs incurring from running a trial system, reimbursing the participants, can be included in the contemplation of an exit strategy. Typically, the intervention and its expected effects and post-project situation of the participants with regard to the system are accounted for in an informed consent process. The informed consent process is likely to address the post -*

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[3] Rauhala, M., Oechsner, S., Ala-Siuru, P., Peyrot, M. Leinonen, E. (2012). "(Im)material Interventions: Toward a Broader Conceptualization of Exit Strategies in AAL Projects". In Ad van Berlo et al (eds.). Tomorrow in Sight - from Design to Delivery: Proceedings of the 4th AAL Forum, Eindhoven, the Netherlands, 24-27/9 2012, 67-69

> *project situation from the perspective of the system and its relationship to the user following participation.*[4]

Most mainstream exit strategies are grounded in such a material interpretation of the introduction of new devices and services into the lives and homes of older people. If a technological system is introduced, used and tested and then removed, the material absence is obvious and material exit strategies need to be in place to account for the "loss" or "harm".

The LILY partners contemplated on another way to view technological interventions and that immaterial exit strategies might be needed alongside the material ones. This would bring other kinds of risks of harm – namely those of social and psychological risks of harm – to the foreground in ending research. According to this view,

> *[A]n immaterial interpretation of a technology intervention is wider than the material one. While the material interpretation can overlook the social and psychological dimensions of research participation, the immaterial interpretation takes into account the more subtle layers of potential benefit and harm. In this way, the relationships that are formed, the attention given to a participant, trust and confidentiality built, the social networks that are created, and the sudden discontinuation of these, are seen as ethically relevant. Therefore, the immaterial interpretation of the technology intervention would call for strategies to prevent the harm that such a discontinuation could cause for a participant.* [5]

The theoretically oriented work on the immaterial interpretation of technology interventions and research participation will be continued beyond the LILY context. This contribution to the discussion on exit strategies in the AAL context is a result of the LILY cooperation and forms an original way of dealing with exit strategies in general.

In the LILY project it became evident that the exit strategies must encounter a number of actors besides the research participants. In particular, ending research for facilitators in the LILY case may mean a change in their in daily work and close contacts with users.

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[4] Ibid.

[5] Ibid.

4.   Lessons learned

There are some useful lessons learned in the LILY context with regard to research ethics to take along to future research and development projects.

4.1 Anticipatory and formal approaches to ethics in AAL

Among the most important observations is the fact that anticipatory and more formal approaches to ethics in research projects are useful in creating a general and shared framework for addressing ethics in an international cooperation project. They are, however, limited if not integrated into the project work. Here translation work is required so that all project partners can have a shared view of the project's commitments.

This part was fulfilled in a comprehensive manner in the Deliverables D1.1/D1.2: Ethical and Legal State of the Art and User Involvement and D4.2: Project Ethics Policy. It is also helpful to create a list of reminders based on more formal ethics documents for the project team responsible for research and piloting. Such reminders function as short-cuts to the rest of the ethics policy although they cannot replace the need for establishing a more detailed background to ethics.

The anticipatory and formal approaches to ethics can also be helpful for the project partners when they produce the necessary documents for formal research clearance from national and local responsible bodies for research ethics.

Such documents have to somehow be interpreted and kept alive during the lifetime of a project. Moreover, it seems that this requires continuity that is inscribed in tasks. This suggests that it is important to have one or more staff members dedicated to the ethics tasks in the project. Resources must be sufficiently budgeted for keeping ethics high on the agenda. This was done in an exemplary manner in the LILY project.

4.2 All partners involved in ethics: different aspects made visible

In the LILY project all partners were involved in ethics work. This seems to be another important aspect of carrying out research in a way that integrates ethics. Through the involvement of the facilitators at the French site in a dialogue about the ethical aspects of their own work it became clear that not only research participants, the future users of the LILY system, but also the facilitators and researchers are in many ways affected from the frequent interaction with users.

Through the involvement of the facilitators it also became evident that the maintaining the continued use of a new system requires a lot of personal investments on behalf of those who introduce the technology. Many skills are required, among them empathy skills. Project workers may not prepared for the amount of personal commitment that continued use sometimes requires.

4.3 AAL can enable reflection on ethics

It is finally worth mentioning that it is possible –provided that there are resources in place to do so – also to reflect on ethics in an AAL project. In this project, new insight into exit strategies was gained through a reflection paper on material and immaterial interventions. This work, which started as an exercise to understand exit strategies in the LILY context, will be continued. Another helpful document for further use is the list of reminders, a kind of checklist, of important matters to keep in mind before, during, and after user involvement activities.

Furthermore, the tasks dedicated to ethics have made it possible to collect the ethics-related concerns raised by the project partners throughout the project. In this way, it was possible to correspond about the potential privacy issues in semantic web solutions and use of RFID. If there are no dedicated tasks for ethics, it may be more difficult to address such issues in the project context.

4.4 Ethics management in LILY

Ethics management supported the partners, who were directly involving users, and provided immediate assistance with emerging ethical challenges. It seems to have been helpful for the partners to be able to get in contact with a project worker responsible for ethics with any issues that that emerged during the course of the research. It was possible for the ethics manager to give immediate support.

Often ethics manager are visitors of sorts in the project, entering the scene in the beginning to construct formal guidelines for the project and then disappearing into the background ready to respond should the project needs their support. In the LILY project, the ethics involvement was continuous and integrated into the entire trajectory of the project. This made it possible to closely follow the activities and proactively ask questions, guide and integrate ethics into the approach.

5.   Concluding words

This document summarizes the ethics-related work in the LILY project and describes the approach taken to ethics in the LILY project: Moreover, it reports about the ethical and legal issues that were identified and were observed and discussed among the partners during the project.

LILY had a strong commitment to ethics as a starting point. It has been the objective of this document to provide a short overview to how this commitment was translated into the project work.

While a number of research ethical issues can be predicted and guidelines for addressing them can be provided in advance, the authors wish to point out that often new ethical dimensions surface in the course of any research and development project. It was suggested that any new issues would be reported as part of the D1.7. In this document, such issues have been documented and discussed together with an overall approach to ethics taken and some original ethics-related work that was undertaken in the course of the project.

Annexed to this document are legislation and policies that were collected during the LILY project to support the project partners in their work.

6.   ANNEX

6.1 Legislation and policies

The following central international and national central guidance and legal documents form the key documents that the LILY partners were recommended to review and study prior to arranging research activities engaging real users, i.e., older persons and any secondary users. In addition, their work was guided by two separate internal LILY ethics documents. Listed below are also national committee, agencies and organizations that can provide further assistance in conducting ethically sound research.

6.2 European Union

6.2.1 Data protection and privacy

- In 2012 the European Commission proposed a reform of the EU's data protection rules to make them fit for the 21st century. The reform consists of a draft Regulation setting out a general EU framework for data protection and a draft Directive on protecting personal data processed for the purposes of prevention, detection, investigation or prosecution of criminal offences and related judicial activities. This process, leading into a new Data Protection Regulation is expected to be finished in 2015.
- Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data
- Directive 2002/58/EC of the European Parliament and of the Council of 12 July 2002 concerning the processing of personal data and the protection of privacy in the electronic communications sector (Directive on privacy and electronic communications)
- Directive 97/66/EC of the European Parliament and of the Council of 15 December 1997 concerning the processing of personal data and the protection of privacy in the telecommunications sector

6.2.2 Ethical issues and research

- 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
- Commission Directive 2005/28/EC of 8 April 2005 laying down principles and detailed guidelines for good clinical practice as regards investigational medicinal products for human use, as well as the requirements for authorisation of the manufacturing or importation of such products

- Various opinions of the European Group on Ethics in Science and New Technologies (EGE) can be relevant for the LILY work. In particular, the recently published opinion number 26, "Ethics and Information and Communication Technologies" (2012), is a recommended reading.

6.2.3 Relevant committees, agencies and organizations

- The European Group on Ethics in Science and New Technologies (EGE). The EGE is an independent, pluralist and multidisciplinary body advising the European Commission on ethics in science and new technologies in connection with Community legislation or policies.

6.3 France

6.3.1 Data protection and privacy

- Law n°78-17 of 6 January 1978
- Law n°2004-801 of 6 August 2004 (modifying Law n°78-17 of 6 January 1978)
- Decree n°2005-1309 of 20 October 2005

6.3.2 Laws regulating health care and social care

- Law no 2004-810 of 13 August 2004 concerning healthcare insurance
- Law n°2002-303 on patients' rights and the quality of the health system
- Law n°2005-370 concerning the patients' rights at the end of life:

6.3.3 Relevant committees, agencies and organizations

- Comités de Protection des Personnes (Committees for the Protection of Persons, CPPs)
- Commission Nationale de l'Informatique et des Libertés (National Commission on Informatics and Liberty, CNIL)
- Comité Consultatif National d'Ethique pour les Sciences de la Vie et de la Santé (National Consultative Ethics Committee on Health and the Life Sciences)
- Conseil National de l'Ordre des Médecins (French National Medical Council, CNOM)

6.4 Finland

6.4.1 Data protection and privacy

- Personal Data Act (523/1999)
- Act on the amendment of the Personal Data Act (986/2000)

6.4.2 Laws regulating health care and social care

- Laki ikääntyneen väestön toimintakyvyn tukemisesta sekä iäkkäiden sosiaali- ja terveyspalveluista 28.12.2012 (980/2012) (Senior Citizens Services Act) into force 1.7.2013
- Terveydenhuoltolaki 30.12.2010/1326 (Health Care Act)
- Sosiaalihuoltolaki 17.9.1982/710 (Social Welfare Act)
- Laki potilaan asemasta ja oikeuksista 17.8.1992/785 (Act on the Status and Rights of Patients)
- Laki sosiaalihuollon asiakkaan asemasta ja oikeuksista 22.9.2008/812(Law for socialcare clients' status and rights)
- Laki sosiaali- ja terveydenhuollon asiakasmaksuista 3.8.1992/734 (Law for healthcare patient and socialcare clients payments about care and service)
- Laki sosiaali- ja terveydenhuollon asiakastietojen käsittelystä 9.2.2007/159 (Law for hcp and scc client information handling/processing)
- Laki sosiaali- ja terveydenhuollon suunnittelusta ja valtionosuudesta 3.8.1992/733 (Law for planning and funding health- and socialcare)
- Laki sosiaali- ja terveydenhuollon palvelusetelistä 569/2009 (Law for voucher)

6.4.3 Relevant committees, agencies and organizations

- The National Advisory Board on Social Welfare and Health Care Ethics (ETENE) (http://www.etene.fi/en)
- Data Protection Board (Tietosuojalautakunta) (http://www.om.fi/en/Etusivu/Ministerio/Neuvottelujalautakunnat/Tietosuojalautakunta)
- National Committee on Medical Research Ethics (TUKIJA) (http://www.tukija.fi/en/)
- National Advisory Board on Research Ethics (http://www.tenk.fi/en/index.html)

In Finland, statutory ethics committees include the National Committee on Medical Research Ethics (TUKIJA) and regional ethics committees. Each of the six hospital districts operating a university hospital must have at least one ethics committee.

6.5 Austria

According to the work plan LILY user involvement activities are not planned to be held in Austria.

6.5.1 Data Protection and Privacy

- Datenschutzgesetz 2000 (Federal Act governing the protection of personal data)
- Gesundheitstelematikgesetz (Federal Act governing health telematics)
- Medizinproduktegesetz (Federal Act governing medical products)

6.5.2 Relevant committees, agencies and organizations

- Datenschutzkommission (Data Protection Commission)

- Ethikkommissionen (Research Ethics Commissions)
- Bioethikkommission beim Bundeskanzleramt (Austrian Bioethics Commission)

There are currently 27 ethics committees in Austria which are dedicated to medical research.

6.6 Further Key Documents

- Charter of Fundamental Rights of the European Union
- European Convention on Human Rights and Biomedicine
- Geneva Declaration of Principles and Plan of Action (Ethical Dimensions of the Information Society)
- Tunis Agenda for the Information Society
- Universal Declaration of Human Rights
- WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects