



ImPaCT in Europe
IMPROVING PERSON CENTRED TECHNOLOGY IN EUROPE

Ethical Framework for the Implementation and Use of Person Centred Technology for Persons with Disabilities

In seeking wisdom, the first step is silence;
The second, listening;
The third, remembering;
The fourth, practising,
The fifth, teaching others.

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Centre de la Gabrielle - Mutualité Fonction Publique action santé social (MFPASS), www.centredelagabrielle.fr

FAIDD, www.kehitysvammaliitto.fi

Hft, www.hft.org.uk

Learning Disability Wales, www.learningdisabilitywales.org.uk

Modem Vzw Gouverneur Kinsbergencentrum, www.modemadvies.be

Nottingham Community Housing Association, www.ncha.org.uk

For more information on the ImPaCT in Europe project, see www.impact-in-europe.eu

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LIST OF KEY TERMS AND ACRONYMS USED

KEY TERMS

Stakeholders

Persons, an organization, or a system affecting or being affected by an organization's actions. In the context of this framework, it refers to users (people with disabilities), service providers, carers (professional or voluntary), staff, relatives, policy makers, researchers and developers, industry and society.

Users

People using the devices. In this context, they are the people with disabilities.

Service providers

People/organisations providing services such as care, education, advice, living accommodation; it includes the organisations' staff.

Carers

People who provide care for persons with disabilities on behalf of a service provider. These people can be employees of the service provider or collaborate voluntarily.

Disability

"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".¹

Policy makers

People influencing societal policies, in this context in the field of e-inclusion, social inclusion, disability, assistive technology.

Society

Self-advocacy groups, generic community organisations, public opinion.

Informed consent

The process by which a participant will be fully informed about the project in which she/he is going to participate. It originates from the legal and ethical right the participant has to direct what happens to her/his body and personal data, and from the ethical duty to involve the participant. Seeking the consent of an individual to participate reflects

the right of an individual to self-determination and also her/his fundamental right to be free from interference, whether physical or psychological, and to protect her/his personal data. These are ethical principles recognized by law as legal rights.² All international declarations stipulate that prior to consent, each participant in a project should be clearly informed of its goals, its possible adverse events and the possibility to refuse to enter or to retract at any time with no consequences. Moreover, no inducement should justify participation in a research project.³

KEY ACRONYMS

AT

Assistive Technology

EASPD

European Association of Service providers for Persons with Disabilities

ICF

International Classification of Functioning

ICT

Information and Communication Technology

NGO

Non-Governmental Organisation

PCT

Person Centered Technology refers to any Electronic Assistive Technology (EAT) designed or used to support independence and safety for people. In case of people with disabilities in the health and social sector, this can include telecare, telehealth and telemedicine, environmental controls, communication and mobility devices as well as Assistive Technology (AT) for desktop, mobile and web applications.⁴

R&D

Research and Development

RESNA

Rehabilitation Engineering and Assistive Technology Society of North America.

1 Art. 1 of United Nations Convention on the Rights of Persons with Disabilities adopted by the General Assembly on December 13th, 2006. The EU has ratified collectively on December 23rd, 2010.

2 Aegis project Deliverable 5.6.1. Ethical Manual. October 2009.

3 Eleonore Pauwels. *Ethics for researchers*. Facilitating Research Excellence in FP7. European Commission. 2007.

4 Definition agreed on with partners of ImPaCT in Europe project.

1. Introduction: the ImPaCT in Europe project

1.1 Objective

The objective of the ImPaCT in Europe network is to “accelerate the effective participation of target groups at risk of exclusion and improving their quality of life” by facilitating the development and implementation of PCT, stimulating the effective use of ICT-enabled services and competence building of the end users of PCT.

1.2 List of the project partners and their working area.⁵

Co-ordinator of the project is the European Association of Service providers for People with Disabilities (**EASPD**). Their work for the equality of opportunities for people with disabilities is based on the interconnected pillars of Impact (European policy), Innovation (Research and Development) and Information. It has four Standing Committees that focus on employment, enlargement, education and EU policy respectively. EASPD also established interest groups on assistive technology, on mental health and on occupational services.

The Centre de la Gabrielle - Mutualité Fonction Publique action santé social (France) assists children and adults with **developmental and learning disabilities** in a Medical and Educational centre for children (IME), a Centre for vocational training (IMPRO), a special unit for people with autistic spectrum disorders, sheltered employment, a residential home and an independent living service (SAMSAH).

The Finnish Association on Intellectual and Developmental Disabilities (FAIDD) works for people in need of support in **learning, understanding and communicating**. They offer information and web services, a Plain Language Centre, Education, Development and Research, a Communication and Technology Centre, Tikoteekki, and a Teaching Materials Centre.

Modem (Belgium), an expert centre for disabled people, provides non-commercial advice on **communication aids and computer accessibility** and ICT training.

Learning Disability Wales (United Kingdom) is a non-governmental organisation in the field of **learning disability** whose membership comprises service providers, parent/carer support groups, self advocacy groups and generic community organisations.

Centro de Educação para o Cidadão Deficiente de Mira Sintra (C.E.C.D., Portugal) provides **intellectually disabled people** with services such as a unit for early intervention in childhood, a special education school, a day care centre, a job training centre, a family support unit and a medical clinic and rehabilitation centre.

AIAS Bologna onlus (Italy) is a non-commercial organisation for people with disabilities and their family members. Its **Assistive Technology Team** operates a regional AT Centre for Emilia Romagna and, on behalf of the City Government, a Centre for adaptation of the domestic environment. The team is multidisciplinary and has over 30 years of expertise in AT and ICT, education, social care, health and architecture.

Hft, United Kingdom, is a national charity providing services for people with **learning disabilities** and their family carers including residential options, domiciliary support, advocacy and supported employment.

Nottingham Community Housing Association (NCHA, United Kingdom) developed the first network specifically to support people with disabilities that delivers telecare through a 24-hour call centre.

The support of the ImPaCT in Europe partners is directed at all kinds of disability but mostly at people with learning disabilities. The outcomes, relevant across disability, include:

- advice to developers and producers towards user led PCT;
- care: medical, rehabilitation, day care, including telecare;
- education, (vocational) training and employment;
- pursuing of leisure activities, social interaction;
- support with residential or independent living;
- training of carers and other stakeholders;
- raising societal awareness (information and web services);
- influencing key policies in the field of inclusion, disability, health, social care.

⁵ EACEA. Application Form ImPaCT in Europe project. 2008.

2. Ethical framework

2.1 Why an ethical framework?

Aiming at preventing societal exclusion of people at risk, the “ImPaCT in Europe” project is of a high moral level. The strategy of working on the improvement of effective participation, quality of life and well-being of these people is smart, as is using person centred technology (PCT) to reach these goals. Although this technology is “person centred” the partners feel the need for an ethical guidance assuring that the user is at the heart of the implementation of PCT and of daily personalised care.

Everyone can follow her/his intuition when ethical dilemmas occur but today’s society presents a wide range of complex circumstances that require more guidance. And since ethical dilemmas usually pass by before we know it, or develop so gradually that we can only recognize them in hindsight, there is a **need for an assessment tool**.

2.2 For whom an ethical framework? Who are the stakeholders?

Health and social care includes a wide range of stakeholders: personnel, volunteers, government, users/people with disabilities and their families, the neighbourhood, the board and management, members, suppliers, etc. In general there are four main parties: government, the market, the providers and the family.⁶

The following parties play a relevant role in the implementation and the use of PCT:

End users (people with disabilities), researchers and developers, manufacturers, service providers, families, volunteers, policy makers, society (public opinion).

2.3 General requirements for the ImPaCT in Europe ethical framework

This ethical framework will need to be **usable for all the project partners in all their working areas** and for **all types of disabilities** they work with (see 1.2).

The project partners expect a **pragmatic framework**, usable in daily work when quick decisions are to be made and which can also be used as a tool to assess whether the PCT is implemented and used for the benefit of the user with disabilities.

6 Translated from Dutch by J.-M. Vanhove. Maarten Janssens en Johan Put *Deugdelijk bestuur in de non-profit Welzijns- en Gezondheidssector*. Steunpunt Welzijn, Volksgezondheid en Gezin. Acco. 2009.

3. Ethics

Ethics can be defined as a **permanent reflection** on moral (written or unwritten) codes of conduct. These codes have their origin in the universal values of the law of nature.

In daily life, people talk about deontology or normative ethics to refer to good habits and duties while in the professions there is a need for codes and standards of accountability to the client or to the service users and to the stakeholders who have given delegation, so to say.

3.1 Ethics and the law of nature

The universal values of the law of nature are the fundamental focus of human beings. According to Thomas of Aquino these are: orientation to preservation of life and to the truth, commitment to the other, the necessity of a balance in societal relations and in the allocation of goods.

On the basis of these values, scientists in bio technologies and medical interventions accepted the following ethical principles: **self-determination** of the people involved, the **usefulness** or **harm** of the intervention and **justice**.

3.2 Normative ethics and deontology

Philosophers usually make a distinction in ethical theories between *metaethics*, *normative ethics* and *applied ethics*.

Metaethics focuses on the issues of universal truths, the will of God, etc.

Normative ethics takes on a more practical task, which is to reach **moral standards** that regulate right and wrong conduct with the good habits that we should acquire and the duties that we should follow. This approach, which judges the morality of an action on its adherence to rules, is also defined as "rule"-based ethics or *deontological ethics*.⁷

Applied ethics examines specific issues such as abortion, infanticide, etc.⁸

3.3 Professional ethics

Professionals carry additional moral responsibilities - they are capable of acting on an **informed decision** because they have received relevant training.

Questions then arise as to the ethical limits of this responsibility and as to how power and authority should be used in service. **Disciplinary codes** allow the professions to draw a standard of conduct preventing exploitation of the user and preserving the integrity of the profession.

3.4 Cultural differences and ethics

Because each culture is a specific system of shared values, beliefs and customs that individuals can use in relation to others and that can be transmitted from generation to generation through learning, **individuals from different cultural backgrounds are exposed to different values and customs**, and accordingly are expected to present different behaviours, including how each individual perceives ethical problems and engages in ethical decision making.⁹

Ethical issues can no longer be considered only within a single nation. Differences in ethical decision making may arise in partner countries due to lower expectations or less stringent regulations, or because lower/higher standards are practised. Cultural traditions may influence societal choices about how to shape a "good life" or about what "independence" means. They may as a consequence also influence political decisions about e-Inclusion and about availability and affordability of PCT devices. Furthermore, professionals have increasing chances of interacting with users (and their families) **with diverse cultural experiences and traditions**. It is a challenge to be aware of these differences in the ethical decision making.

3.5 Conclusion: basic elements of the framework

In working with (disabled) people carers have several identities. They act as **human beings** in relationship with others and as **professionals** in relationship with users and stakeholders. Consequently, they will need to adhere to the universal values of the law of nature, to the deontological standards of the normative ethics in working with people and to the disciplinary codes of the professional ethics.

The **universal values** of **self-determination** (autonomy) of the people involved, the **usefulness** (quality of life) or (absence of) **harm** of the intervention and **justice** (social integration) need to be included in the framework.

Deontological codes cover items such as e.g. professional secrecy and privacy, carefulness in action and advice, duty to inform the parents. Even when not written into a code, the application of these principles is usually expected of all stakeholders, employees, volunteers, elected representatives and so on.

Professional codes of practice and disciplinary codes are applicable for those who have received relevant training in the different working fields. They include impartiality/objectivity, openness/full disclosure, confidentiality, due diligence/duty of care, fidelity to professional responsibilities and avoiding potential or apparent conflicts of interest. The question is whether they all can be expected of unpaid carers who mostly have not received the relevant training.

7 The term *deontological* was first used in this way in 1930, in C. D. Broad's book, *Five Types of Ethical Theory*.

8 J. Fieser, University of Tennessee, Martin, U.S.A. <http://www.iep.utm.edu/ethics> (07.11.2010).

9 Lin, Chieh-Yu; Ho, Yi-Hui. *An examination of cultural differences in ethical decision making using the multidimensional ethics scale*. Social Behavior and Personality. October 1, 2008.

4. Ethical behaviour – basic values

A widely used framework in health and social care, that is particularly useful for this guidance, was prepared by Beauchamp and Childress. They described four major principles that apply to health ethics: autonomy, beneficence, non-maleficence and justice. Respect for **autonomy** means respecting the decision-making capabilities of autonomous persons: enabling individuals to make reasoned informed choices. **Beneficence** is about balancing benefits of treatment against risks and costs: the healthcare professional should act in a way that benefits the patient. **Non-maleficence** means avoiding causing harm: healthcare professional should not harm the patient. All treatment involves some harm, even if minimal, but the harm should not be disproportionate to the benefits of the treatment. **Justice** refers to distributing benefits, risks and costs fairly: the notion that patients in similar positions should be treated in a similar manner.¹⁰

4.1 Paradigm shift

During the last decades there has been a paradigm shift in societal view of persons with disabilities.

In the **medical model** of disability the focus was put on individual impairments. People with disabilities were considered as unable to function in society, only needing lifelong care and treatment in distinct, specialised schools and institutes.

In the **integration model** of disability growing attention was given to the abilities of persons with impairments. Service provisions tried to use and develop these abilities so persons with impairments could lead a so-called normalised life.

The **democratic model** of disability recognises people with disabilities as citizens with the same rights as all others. Society enables this through policies and legislation on equal opportunities and inclusion.¹¹

4.2 Self-determination or autonomy

Autonomy (self-determination) is the notion of deliberated self-rule or the ability of the individual to make choices. The autonomous individual acts freely in accordance with a **self-chosen plan**. A person of diminished autonomy, by contrast, is in some respects controlled by others or incapable of deliberating or acting on the basis of his or her desire and plans. Virtually all theories of autonomy agree that two conditions are essential for autonomy: liberty (**independence** from controlling influence) and agency (**capacity for intentional action**).¹²

Based on this principle, people with disabilities have the right to choose for themselves and to organise their life preferably in usual conditions. This implies the recognition of their individual needs and wants.

The degree of disability can never be decisive for the way people want to live, work, get education or use their leisure time, neither can this determine which relationships they can have or not. This requires an open, transparent service provision.¹³

4.3 Beneficence

Beneficence means working for the benefit of the individual. Translated into working with people it is about doing our best for those whom we support. It may mean doing research for the benefit of the user, looking for solutions to their problems, continuously assessing the **usefulness** of the intervention, etc.

4.4 Non-maleficence

The term **non-maleficence** derives from the ancient maxim “Primum non nocere” which means “First, do no harm”. Safeguarding the **safety** of PCT devices and preserving the **privacy** of the user are applications of this ethical value, and so is prevention of exploitation of the user.

4.5 Justice

Justice means, a. o. treating all people, including the disabled, as citizens with **equal rights** and opportunities, i.e. the right to decent education, to grow up to vote, to marry and have a family and to express opinions with help and support to do so wherever and whenever necessary. Societies would be unjust if they allowed only segments of the population to advance and live in comfort.¹⁴ In this context, it means assuring that disabled persons should have **access to all services needed**, e.g. ease of use of products and **affordability** of the necessary devices and to take care of those who cannot take care of themselves. This may require awareness-raising including a change of the generally-held image of people with impairments: the latter are after all the primary stakeholders of the care.

10 Beauchamp and Childress. *Principles Biomedical Ethics*, OUP, 5th Edition, 2001.

11 Translated from Dutch by J.-M. Vanhove. Van Gennep & Steman. *Zorg voor mensen met een verstandelijke handicap*. 1997.

12 Beauchamp and Childress. *Principles Biomedical Ethics*, OUP, 5th Edition, 2001.

13 Translated from Dutch by J.-M. Vanhove. *Samen werken aan een goed leven*. Eindrapport Project Zeggenschap. Standaarden en Indicatoren. Stichting Perspectief. Utrecht, Nederland. Juni 2010.

14 Neena Gill. *ICT, the Elderly and Emerging Global Markets, World leading expert talks on Privacy, Ethics, Technology and Ageing*. Including Seniors in the Information Society. Interview. 2008.

5. Ethical behaviour – deontological and professional codes in care

5.1 Ethics and care

Ethics of care refer to ethical standards developed for the care professions. They will be based on the basic values of self-determination, well-being (beneficence and non-maleficence) and justice.

People with disabilities, also those with severe and profound disabilities, can, with the right help and support, make important choices and **express preferences about their day-to-day lives**. There is no **self-determination** unless users with disabilities are involved in all decisions concerning themselves.¹⁵

Involvement means at least that users have a “**say**” about who supports them and that they **decide** how best to spend their resources. “**Say**” is about development towards a proper identity, getting the opportunity to discover the quantity of support they need.¹⁶

The process of allowing the user to manage her/his own life and making own choices changes “care” into “support” which starts from the existing **social network**.

Strengths become visible through victories of people in difficult circumstances (the survivor’s pride). This gives room for the building of positive identities and social roles **strengthening self-esteem**. This process of personal development means also that one should aspire to the care which is **least radical**: ambulant is preferred to residential, general to (disability) specific and this as much as possible in the natural context of the person involved. The professional caring system only acts when the first one is not able to offer adequate support.¹⁷

The most challenging ethical issue relevant to autonomy in the case of people with (learning) disabilities is that of **consent**. In the UK it was made compulsory for any health professional examining, treating or caring for a competent adult patient to obtain their consent. Legislation on informed consent exists in several countries, certainly in the medical field.

5.2 Ethics and personalised care

Personal support means that people receive an adequate support to live a meaningful life with normal daily opportunities, in accordance with their needs.¹⁸

This does not mean that disabled people are expected to do everything themselves, rather that they are expected to have the biggest say in what they do and how they live their lives and to take responsibility for their lives. Therefore, resources should be allocated and services delivered in ways that personalise responses to need, **enable people to make choices** and to be empowered to help themselves.¹⁹

Personalisation of care means working **with** the individuals not **for** them; it means **coaching users**, adapting care with changing individual needs, setting up services based on unknowns, thus taking positive risks.

5.3 Ethics and person centred technology

The European project “Tate” has demonstrated that PCT can bring a lot of benefits to users by extending the time they can live in their preferred environment, by augmenting their human capabilities and autonomy, by enhancing security and by preventing social isolation, etc.

Yet, there are numerous ethical and privacy concerns posed by such technology, certainly in the areas of e-health and telemedicine. Communication hardware coupled with sensors has created the potential to **monitor** vulnerable people **remotely** with immediate support when needs arise rather than having to be supported by staff directly. This will change the way **staff and family carers provide support**.

Care based on the ethical principle of beneficence will balance the beneficial aspects of PCT with possible risks or disadvantages.

15 Dr. Stephen Beyer, Dr. Jonathan Perry, Andrea Meek. *A Guide to implementing Assistive Technology for people with learning disabilities*. A product of the TATE project., Welsh Centre for Learning Disabilities. School of Medicine, Cardiff University. March 2008.

16 Translated from Dutch by J.-M. Vanhove. *Samen werken aan een goed leven*. Eindrapport Project Zeggenschap. Standaarden en Indicatoren. Stichting Perspectief. Utrecht, Nederland. Juni 2010.

17 Translated from Dutch by J.-M. Vanhove. Van Gennep & Steman. *Zorg voor mensen met een verstandelijke handicap*. 1997.

18 Translated from Dutch by J.-M. Vanhove. *Samen werken aan een goed leven*. Eindrapport Project Zeggenschap. Standaarden en Indicatoren. Stichting Perspectief. Utrecht, Nederland. Juni 2010.

19 *Improving the Life Chances of Disabled People*. Report of Strategy Unit of the Prime Minister, UK. 2005.

In the medical tradition, outcomes are usually assessed in randomized controlled trials through clear and well-understood criteria of safety and clinical effectiveness. But are these criteria useful or sufficient when applied to the evaluation of ICT in healthcare? They are not. **ICT-related applications** are complex and diverse **and require a different and more encompassing approach to evaluation.**²⁰

There is also the ethical principle of justice. Due to economic and social factors, not everybody has **access to technology**. People unable to grasp technology sufficiently will not use technological devices or they will not use them in the right way. Vulnerable people have to learn how to use technology. Thus technology will discriminate just as education does.²¹

5.4 Summary

Applying the basic value of self-determination in care means **that users are involved**: that they are informed, have a say, make decisions about their life. **“Care”** becomes **“support”**: **this means focusing on the empowerment of the user**, aiming at an **increase in personal development**, in collaboration with her/his social network. The support starts preferably at a basic level. Personalised care will be organised in accordance with the individual needs of the user. The **carer becomes a coach**.

Person centred technology increases the opportunities of coaching, **changing the role** of the **carer**. The benefits or disadvantages of the technology need a specific evaluation. The risk for a digital divide between users and (not capable) non-users must be avoided.

20 *Ethical Perspectives in Evaluation of Telehealth*. Tony Cornford and Ela Klecun-Dabrowska (2001) Cambridge Quarterly of Healthcare Ethics, Volume 10(2) 161-169.

21 Yolande Berbers. *Privacy, Ethics, Assistive Technology and Keeping People included*. Including Seniors in the Information Society. Interview. 2008

6. Ethical behaviour when facing problems in the process of implementation and use of PCT

Ethical problems may occur in all stages of the process of implementation and use of PCT in a daily working routine. Before describing these, it is necessary to agree on the different stages of the process. The following chapter will describe possible ethical risks and the appropriate ethical attitude; it will also give information on relevant European projects for every stage of the process.

6.1 Process of implementation and use of PCT

For PCT to become enabling, i.e. allowing a higher degree of independence for disabled people, several consecutive steps of a process must be taken:

- Analysis of the needs and preferences of the user for the use of PCT;
- Selection of the most adequate PCT-device on the market;
- Implementation and use of PCT in service provision and daily care, including training of carers;
- Assessment of benefits in balance with risks (the degree of independence realised, improvement of quality of life);
- Feedback to R&D and industry to user led PCT: raising awareness;
- Feedback to government: influencing (funding) policy promoting social benefits.

Every actor with their proper decision-making power and interests will need to adopt an ethical attitude in every step of this ongoing process. The ethical framework must be of help offering ethical codes for each of these steps.

6.2 Analysis of the needs and preferences of the user of PCT

6.2.1 Ethical risks

Often a **concept of "prescription"** is used to select the device, which links the type of service provided to the origin or type of disability, rather than to the abilities, needs and preferences of the person.

Many factors must be observed to determine the most adequate device. Unfortunately, these factors sometimes become only apparent when individuals stop using AT-devices, which is not always known by the service provider. High rates of abandonment of assistive technology ranging from 8% to 75% (Garber & Gregorio, 1990; Gitlin, 1995; Phillips & Zhao, 1993; Tewey, Baranicle & Perr, 1994) give the impression that not all the influencing elements have been assessed. Sometimes forgotten reasons for **discontinuance** are the lack of acceptance of the disability,

the lack of self-confidence, insufficient (digital) literacy (does the user understand the implications of the choice?) or the lack of training. Thus it is necessary to assess these factors as well.²²

It must be said that not only functional aspects are decisive for the use of a device. Not taking into account the **preferences** means that the user has not been involved in the selection process. Sometimes the assessment does not take into account the **expected evolution** of the impairments and changing needs.

6.2.2 Ethical behaviour

It might be simpler and more cost-effective for service providers to install a "core package" of devices. However, devices that are appropriate for one user might not be suitable for another one. A device will only be a solution when it is the answer to the **individual's needs** in her/his context and for the activities in which her/his impairments cause a handicap. Only accommodating the needs of a person with disabilities enables her/him to live with maximum independence, privacy and dignity.²³ An assessment should be client-centred and needs driven.

Functional needs must be defined using (classifying) **diagnostics, managing the expected evolution of the disability of the user** on the long term. Assessments need to take into account the living context of the user and must be carried out **in co-operation** with the user's daily close communication partners. **Preferences should be taken into account as well as abilities.** Consequently, the assessment will best be executed by a **multidisciplinary** team.

FAIDD carries out an assessment for the use of the computer mainly in the different environments of the client by a team consisting of an occupational therapist (who shall bear the main responsibility), an IT specialist and a speech therapist.²⁴

The **International Classification of Functioning (ICF)** may be usable as a common language for the assessment of needs, linking clinical and rehabilitative services. ICF emphasizes the need to look at the complete lived experience of disability.²⁵

6.2.3 Interesting European projects

- The ATES project Murinet puts forward the possibility to use ICF as common language for needs assessment;
- The AWAKE model of ICT4All project is an example of an assessment model;
- The TOBI project will develop tools based on users' needs.

22 *Factors on Assistive Technology Device Abandonment: Replacing "Abandonment" with "Discontinuance"*. ATOMS Project Technical Report. 2006.

23 Yalon-Chamovitz. *Assessment Process of the Use of Computer*. FAIDD. 2009.

24 *Assessment Process of the Use of Computer. Case study*. FAIDD

25 *Ethics and Human Rights*, WP 4 of MURINET-project. Multidisciplinary Research Network on Health and Disability in Europe.

6.3 Selection of the most adequate PCT device on the market

An analysis of needs will reveal the requirements of the solution. With this analysis a type of device can be proposed. The next step is to select the device on the market that is most appropriate for the user.

6.3.1 Ethical risks

The selection process does not always lead to the most adequate device. This may originate from the fact that advisors sometimes are **not familiar** with the (commercial) market of devices which is fragmented into many (mostly small) manufacturers.

This commercialisation and fragmentation jeopardizes **objective information gathering on behalf of the user**. There is a need for independent advisors to carry out a search from the point of view of the disabled user. "Independent" means not having commercial interests.

Because of reimbursement policies, in most countries professional advisors choose the device. **Users** themselves are **practically not involved** in the selection process. Furthermore, they often are not given a chance to try out the device for a certain period. The **influence of reimbursement policies** should not be underestimated in this process.

Another possible underestimated aspect is that of aesthetics of a device. Using technology that others do not use can mark people out as different from others and can thus be **stigmatising** and create resistance from the (potential) user.

6.3.2 Ethical behaviour

An ethical choice of a device will be based on **objective information** from **independent professionals** and preferably only made after a **tryout** period.

6.3.2.1 Inform the user objectively of existing solutions

Only adequate and accessible information about opportunities and inconveniences of PCT devices can lead to an adequate choice for the user. This is the interpretation of the ethical principle of beneficence. Sharing transparent information on AT also means **treating people with disabilities as consumers**, not as "patients".

Information should also be given on reimbursement policies preventing problems of affordability. **Showing users how to use AT** for their own benefit is the most effective way of informing them. Carers have an important role in this stage being the intermediaries of the users. Fortunately, in several

countries they can contact independent knowledge centres, providing assessment tools (e.g. Tikoteekki, KOC Flanders, ...).

6.3.2.2 Be aware of stigmatisation

Link and Phelan (2001)²⁶ state that a stigma arises because people distinguish and label human differences. Dominant cultural beliefs link labelled people to undesirable characteristics and negative stereotypes. Labelled people experience status loss and discrimination that lead to unequal outcomes. This, in turn, can lead to anxiety, depression, a distorted self-image and low self-esteem. Stigmatisation is certainly a reason for non-use of devices with elderly people.

Parette and Scherer (2004)²⁷ discussed a number of issues related to stigma, of which some are particularly relevant to AT: device **aesthetics and universal design**. Aesthetics must be taken into account when choosing the device but certainly also in the designing stage.

6.3.2.3 Let the user decide for her/himself

To leave the device choice to the user is an example of self-determination. In this way preferences are taken into account and not only (technical) needs, although these should always be predominant. The best way to realise this is to enable a **tryout** of the device in co-operation with the family.

Considering the user as an autonomous person, all decisions must be taken by the user or with an **informed consent** starting with the choice of the PCT solution.

Certainly when there is a significant difference of opinion between the user and the carers about the choice of a PCT, it is absolutely necessary to ask for an **informed consent**.

6.3.2.4 Arrange an informed consent

The following definition of "informed consent", used for research is also applicable for care in general: "Informed consent is the process by which a participant will be fully informed about the research in which she/he is going to participate. Seeking the consent of an individual to participate in research reflects the right of an individual to self-determination and also her/his fundamental right to be free from (bodily) interference, whether physical or psychological, and to protect her/his personal data. These are ethical principles recognized by Law as legal rights. A distinction between three informed consent elements is possible: the information given, the capacity to understand it and the voluntary nature of any decision taken."²⁸

In practical terms people should be given as much **information** as they reasonably need to make a decision about the nature, significance, implications and risks of the proposed solution.

26 Bruce G. Link and Jo C. Phelan. *Conceptualising Stigma*. Annual Review of Sociology. 200, p. 363.

27 Parette and Scherer. *The Stigma associated with the use of Assisted Devices*. Limerick Student Journal of Sociology. 2004.

28 Aegis project D.5.6.1. Ethical Manual.

The consent should be given **voluntarily** and not under any form of duress or undue influence from professionals, family or friends and may be written, oral or non-verbal. This also means that giving responsibility to users must be based on an **assessment of their real (mental) capacities**. For people with mental disabilities this seems to be difficult to apply. The U.K. Mental Capacity Act, which came into force fully in October 2007, puts forward as fundamental principles that a person must be assumed to have capacity unless it is established that she/he lacks it and that she/he is not to be treated as unable to make a decision unless all practicable steps to help her/him to do so have been taken without success or merely because she/he makes an unwise decision. A decision made on behalf of a person who lacks capacity must be in her/his best interests; and before the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action. Judgements of the best interests should strive to find the right balance between quality of life outcomes including independence and safety.²⁹

6.3.3 Interesting European projects

- An element of the Awake model of the ICT4All project is on increasing the knowledge of care professionals;
- Use of consent form and user involvement: <http://www.enable-project.eu>.

6.4 Implementation and use of PCT in care

Implementation and use of PCT in service provision and daily care include putting PCT into service, training of users and staff, integration into care, etc.

6.4.1 Ethical risks

It should not be forgotten that many of the management practices associated with institutions in the past were adopted because of convenience to the organisation according to Goffman's (1961) concept of total institutions. Such practices included what Goffman termed as **rigid routines, block treatments, de-individualisation and the distancing of staff from clients**.³⁰

There is still a lack of appropriate ways of systematically involving people with disabilities, especially intellectual disabilities, in planning processes.³¹

Implementing and/or using PCT requires sufficient digital literacy. Carers are not always familiar with implementing PCT since they were/are used to support from specialist advisors. Users do not always have the needed (digital) literacy to use PCT. Both are reasons why the chosen **PCT may not be effective**.

Enabling technology may include personal surveillance and an **invasion of privacy**. There are certainly ethical concerns when behaviour is monitored. Already in 1996 Doughty et al. identified a progression in telecare services from reactive systems requiring user-initiation, through automatic sensor-based systems, to third generation "passive" systems in which possible acute situations are predicted on the basis of "lifestyle monitoring".³²

Although individual sensors used for lifestyle monitoring are unobtrusive and passive, the data collected is of a personal and sensitive nature because it describes habit, **behaviour** and the frequency of performing tasks relating to self-care. Do carers have the right to continuously monitor people in their daily environment? Particular concerns are raised when (medical) **data need to be exported** from the home for analysis and may be used inappropriately for example to profile a patient or to exclude her/him from certain programmes or services.

The area that provides most potential conflict with individual rights is determining the level of **risk** that is acceptable given the needs and abilities of the individual, the situation of the carers and the potential liability of any specific service provider. Where individuals become dependent on technological solutions, failure in the device can have a huge detrimental effect on them. When a call centre is used, an extra element of risk can be the delay that will be incurred whilst staff respond to the alert received from the call centre. Also, there is the possibility of technological problems with the AT.

6.4.2 Ethical behaviour

6.4.2.1 PCT must be integrated in a care plan

Services **achieve quality of life** (QoL) if they support people individually in living their lives as full citizens, and do not intend to fit them into standardized models and structures.³³ The quality of life concept is increasingly being used in the field of intellectual disabilities as a conceptual and measurement framework for programme planning and evaluation. It has an important role on all levels of planning and evaluation: individual level, organisational level and systems or authority level.³⁴

29 J. Perry and S.R. Beyer. *The impact on objective quality of life outcomes of assistive technology in residential services for people with learning disabilities*. Journal of Assistive Technologies, Volume 3,1 (209). October 2009.

30 Dr. Stephen Beyer, Dr. Jonathan Perry, Andrea Meek. *A Guide to implementing Assistive Technology for people with learning disabilities*. Welsh Centre for Learning Disabilities, School of Medicine, Cardiff University. March 2008.

31 *Assessment Process of the Use of Computer*, FAIDD.

32 Kevin Doughty. *Lifestyle monitoring – extending telecare services into prediction and prevention*. Journal of Assistive Technologies, Volume 2 Issue 1 March 2008, pp. 35-42.

33 Astegger & Plaute. *Promoting Inclusion and Quality of Life: Quality of Planning Processes and Service Provision*. 2010.

34 Schalock et al. *The conceptualisation and measurement of quality of life: implications for program planning and evaluation in the field of intellectual disabilities*. Evaluation and Program Planning. May 2008.

A care plan will **put forward outcomes** to be achieved by/with the user trying to improve her/his quality of life. These outcomes will be pursued from the simple daily functions (eating, washing, dressing,...) through building relationships, being part of the community (shopping, using local shops, being involved in local organisations,...) to making important decisions such as where to live, who needs to support her/him, who needs to look after her/his personal money.

Although achieving quality of life for the PCT user should be the primary goal of the installation, **other outcomes can also influence the care plan** such as saving finances, staff time or other resource savings, that can then be re-allocated to deliver quality of life for the individual or other people with disabilities.

6.4.2.2 Do not forget the existing social network

An empowering service provision gives particular **attention to the social networks** of people and tries to strengthen or repair the existing networks, to start new networks and to create, where necessary, societal support systems (e.g. buddy systems, working in group with peers).³⁵ In this collaboration, **roles and responsibilities of the actors** involved must be clear as far as dependency and decision making are concerned.

6.4.2.3 Wherever possible, have users organise their own support

Self-determination for users may mean that they are given the opportunity to organise themselves the support they need in order to **live the life they choose**. Quality of life means living as much as possible under 'normal' circumstances. A (professional) caring system should only start delivering the needed support when the existing network fails to give the necessary support.

This must be possible even for people with intellectual impairments having the same rights and duties as any other citizen in society. There should be no patronizing.³⁶

6.4.2.4 Be aware of transfer of control using PCT

The introduction of AT involves a transfer of control from a person (staff or user) to a technological system, and a change in the standard decision making process reducing the need for constant staff presence. This is sometimes seen as a threat by professionals rather than an opportunity.

However, electronic assistive technology presents an added bonus: it has no history or tradition of belonging to

any particular staff group and therefore it can be used to breaking down professional boundaries. It can provide the opportunity for **new kinds of workers and new types of roles** to develop, and this is essential in the current climate of social change.

The requirement to develop telecare services can also be a stimulant to cultivate **additional entrepreneurial skills**, to take risks and to take more personal responsibility for actions and decisions.

Carers become coaches interacting with people in an affective and empathetic manner, guiding the active interaction between human being and computer.

6.4.2.5 Manage risks

The level of **risk** that may be caused by the use of PCT has to be managed, meaning that these risks must be evaluated considering the abilities and the right to autonomy of the individual, the situation of the carers and the potential liability of any specific service provider.

When telecare systems replace traditional alarms, service providers must change their **operating procedures** to deal with increasing numbers of people who need emergency responses to a range of different emergency situations. The telecarers or teleresponders will need immediate access to properties that they have probably not previously visited. This will need a reliable method of gaining access using **digital access codes**, which is acceptable to insurance companies, to service users and their families, and to the emergency services.

In the context of telemedicine, also the risks and effectiveness of the self-administration of medication have to be evaluated.

6.4.2.6 Do not forget the right to privacy

The complexities and intricacies of issues relating to privacy and data protection have received huge attention from policy makers, regulators, academia, the mass media and many other stakeholders, including ethicists. Some years ago, Roger Clarke identified four dimensions of privacy: privacy of the person, of personal behaviour, of personal communications and of personal data.³⁷

Telecare must maximise benefits to justify any reduction in privacy. Any piece of technology that collects information should make it clear that it is capable of doing that, on what channels it is collecting information and of what type, what sorts of networks it is connected to, who owns those networks, etc.³⁸ Service providers must also **inform**

35 Translated from Dutch by J.-M. Vanhove. T. Van Regenmortel. *Empowerment, Een krachtgerichte benadering*. 2007:265

36 Translated from Dutch by J.-M. Vanhove. Van Gennep & Steman, 1997. *Zorg voor mensen met een verstandelijke handicap*. In Smit & Van Gennep. 2002:9.

37 Roger Clarke. *Introduction to Dataveillance and Information Privacy and Definitions of Terms*'. August 2007.

38 Adam Greenfield. *Assistive Technology, Privacy, Design and the Elderly*. Including Seniors in the Information Society. Interview. 2008.

the users about what information will be collected and for which purpose. Personal data should be securely stored in the home of the service user and only exported using good practice standards and agreed joint **protocols**.³⁹ Exporting of data might then be performed on a “need to know” basis, and limited to specific individuals in organisations for whom access has been agreed.

6.4.2.7 Empower users and carers

To make PCT effective, carers will have to help the person with disabilities to interact with PCT. We need to **educate users**, support them in taking ownership of the new technology. That is empowering.

In a first stage, this includes addressing the ability of the user to carry out daily life activities and enabling her/him to develop self-confidence, life skills, self-sufficiency. In a second stage, it means addressing ICT skills and training in using the device. It is also important to provide **competence-building opportunities for staff and relatives**.

6.4.3 Interesting European projects

- Privacy and security: Oasis project, <http://www.oasis-project.eu/>;
- Power and transparency: confidentiality of communications – transfer of confidential information – public information: D4Allnet project (Stakes, Finland);
- User empowerment: EUSTAT. <http://www.siva.it/research/eustat> (1997-1999).

6.5 Assessment of benefits of PCT in care

6.5.1 Ethical risks

Whereas telecare can increase social contact through email, Skype video conferencing and other tools on the one hand, it may, on the other hand, cause **loss of significant social (human) contact** because it reduces the reliance on carers. This is a real threat for people with learning disabilities considering that they have very restricted social networks outside family circles and care staff. For example, Robertson et al. (2001) reported that the median size of social networks of a sample of 500 individuals with learning disabilities living in the community was 5 people (range 0-20). The median size was reduced to only two people when staff were excluded.⁴⁰

Moreover, AT may cause other unforeseen and undesired side effects. Technological devices supporting cognitive development can cause **cognitive decline**, meaning that the user no longer develops her/his cognitive abilities.

6.5.2 Ethical behaviour

The principal ethical concern is that telecare should not socially isolate people and that quality of care be maintained.

6.5.2.1 PCT must not replace social contacts

There need not necessarily be a contradiction between technology and human beings. **Telecare should not be seen as a substitute for staff contact** but should be combined **with** direct social care and informal support to maximize people’s motivation and enablement by facilitating carer involvement and developing the individual’s social engagement.⁴¹ PCT should be part of a global care system in which care workers remain visible. The importance of human relationships in the introduction of PCT-based care must not be forgotten. When PCT is only implied as a method to improve efficiency, there is a risk of isolation.⁴²

Furthermore, **disabled people do not live in isolation but in a context**. There are much wider social contacts, such as local facilities, walks to local shops, etc. where people can go and interact with other people.⁴³

If social isolation is increased, consideration should be given to compensatory strategies, such as fostering relations with neighbours, or exploring more leisure activities with social contact in mind (and staff may need to be involved). It should be added that telecare may also create **more “alone time”**.

6.5.2.2 Monitor the effectiveness of PCT

The principal ethical concern here is that services should be tailored to the **individual**, not the other way around. This requires **effective** care assessment.⁴⁴ A service must be evaluated and measured by verifying the impact the service has on the person with a disability in terms of achieving goals and outcomes.

A change in management culture is taking place in the sector of service provision for people with disabilities. Across Europe there is an emerging and strong tendency to identify quality by the outcomes of a service in terms of full participation, inclusion in society and full citizenship of people with disabilities. This quality of life (QoL) approach sets the scene for the evaluation of the quality of a service.⁴⁵

39 J. Perry and S.R. Beyer. *The impact on objective quality of life outcomes of assistive technology in residential services for people with learning disabilities*. Journal of Assistive Technologies, Volume 3,1 (2009). October 2009.

40 Dr. Stephen Beyer, Dr. Jonathan Perry, Andrea Meek. *A Guide to implementing Assistive Technology for people with learning disabilities* Welsh Centre for Learning Disabilities, School of Medicine – Cardiff University. March 2008.

41 J. Perry and S.R. Beyer. *The impact on objective quality of life outcomes of assistive technology in residential services for people with learning disabilities*. Journal of Assistive Technologies, Volume 3,1 (2009). October 2009.

42 Jean Claude Burgelman. *Economics and the Elderly: How ICT can help people remain at work. Including Seniors in the Information Society*. Interview. 2008.

43 Marion Hirsh. *Assistive Technology, Education and the Elderly*. Including Seniors in the Information Society. Interview. 2008.

44 Dr. Stephen Beyer, Dr. Jonathan Perry, Andrea Meek. *A Guide to implementing Assistive Technology for people with learning disabilities*. Welsh Centre for Learning Disabilities, School of Medicine. Cardiff University. March 2008.

45 EASPD. *Memorandum on a European Quality Principles Framework*. Brussels, December 7th 2006.

6.5.2.3 Interesting European projects

- Mitigation of effects of disability and increased quality of life: ENABLE project: <http://www.enable-project.eu>;
- Quality of life: <http://QOL.euproject.org>;
- Benefits of using PCT for people with learning disabilities and their carers: TATE project: <http://www.tateproject.org.uk>;
- Development of measurements and instruments to assess quality of life <http://cordis.europa.eu/fetch?CALLER=FP6>;
- Quality indicators on AT: <http://www.qiat.org>.

6.6 Feedback to R&D and industry on user led PCT

6.6.1 Ethical risks

Unfortunately, people with functional impairments are sometimes confronted with **inaccessibility, complexity of usage** of PCT devices and inaccessible, complex manuals. Furthermore, devices bought from different manufacturers may be incompatible with each other, the reason being that **researchers and industry are not aware of real needs**.

6.6.2 Ethical behaviour

Research should be carried out for the direct benefit of the user in order to justify risks more than those encountered in normal life.

6.6.2.1 Promote the concept of **Universal Design**

The use of systems that are widely available on the market, the so-called “mainstream” ICT, should be privileged. They tend to be cheaper, more reliable and compatible with other systems/products. High technology markets should only sell assistive technology for specific needs when unavoidable, i.e. when mainstream devices (i.e. devices used by everyone) are not adequate.

A universal accessibility of the mainstream market is the fundamental prerequisite to realise full participation for people with disabilities. This can only be achieved in the designing stage of PCT. This so-called concept of “**Universal Design**” should be encouraged. In this designing stage it must also be possible to pay attention to aesthetics of devices so as to prevent stigmatisation.

Another central idea of “**Universal Design**” concerns adaptability of systems and services to the needs and preferences of every single user. The adaptation must be guaranteed at run time. **Adaptability** in environment asks for interoperability and standardisation.

6.6.2.2 Inform on real needs and involve the user

Questions may arise whether the market gets feedback from the users. Carers have some responsibility for awareness raising as intermediaries because end users mostly do not buy the devices themselves. Information on the reasons for use or non-use of a device may be interesting for R&D and industry.

The emphasis for the development of PCT must not be on technology itself, but on its **useful functionalities** compatible with the needs of people with impairments. The best informers on these are the users themselves. This is why **users must be involved**. Involving people with disabilities in an appropriate way in informing or shaping the research process respects them as active participants in the research and not as passive objects of research.

The Irish National Disability Association (NDA) has worked out a guidance promoting the inclusion and participation of people with disabilities in research and research dissemination.⁴⁶

6.6.3 Interesting European Projects

- Universal accessibility and user involvement: AEGIS project (Open Accessibility Framework): <http://www.aegis-project.eu>.
- Interoperability: OASIS-project (Open architecture for Accessible Services Integration and Standardisation).

6.7 Feedback to government and society

6.7.1 Ethical risks

Society tends to **categorize people** according to their situation of disability on the same social processes as for stigmatisation.⁴⁷ People distinguish and label human differences to undesirable characteristics and negative stereotypes. This results in loss of status for labelled people and **discrimination**. The role of carers in this can be drawing attention to abilities of people with impairments instead of disabilities.

Governments do not know which policy to use towards disabled people. PCT is part of the “technological revolution” in times of economic and demographic concerns. On the one hand, there are growing **economic concerns** over resources required for the welfare of vulnerable groups whilst on the other hand, there are growing pressures, particularly in the western world, that the **rights of all citizens** should be upheld. Given that the societal cost of making mainstream solutions accessible or to producing AT-solutions is high, the mentioned pressure can cause conflict in the traditional provision for support to vulnerable groups, e.g. reimbursement: what is luxury, what is not? This might mean that a person is denied an AT which she/he would really like, because a judgement has been made that the money could be spent more usefully elsewhere.

⁴⁶ *Ethical Guidance for Research with people with disabilities*. Disability Research Series. NDA. October 2009.

⁴⁷ Bruce G. Link and Jo C. Phelan. *Conceptualising Stigma*. Annual Review of Sociology. 200, p. 363.

6.7.2 Ethical behaviour

Justice extends beyond the individual. It relates to a moral obligation to act on a fair adjudication between conflicting claims. Government should organise **awareness raising** campaigns to change the generally held image of people with impairments stressing they have more abilities than disabilities.

Society/government must also decide how they want to improve the quality of life of people with impairments: by funding AT or by organizing and subsidizing personal assistance and care? One may add other questions, such as: how can ICT for special needs be ensured in other than public services?

Decisions have to be made about the allocation of the constrained resources available for human services. To prevent exclusion and discrimination **legislation** may be needed on the accessibility of mainstream products, the affordability of the devices and the level of digital literacy.

The conflict between economic and demographic pressures that may lead to a reduction in resources and the pressure to maintain and enhance the quality of life for all members of society, including vulnerable groups, will require initiatives that will help reduce the impact upon them. PCT could be one of these initiatives.

PCT reducing the reliance on staff input could be a significant contribution to both the quality of life of people with learning disabilities and to the national problem of the increasing dependency ratio (between those who need support and those able to provide it). Service providers, consequently, will often act as the "gatekeeper" to the use of technology in supporting an individual. They therefore will have to promote **social benefits**.⁴⁸

6.7.3 Interesting European Projects

The European MINAmi-project (addressing ethics in the design of ambient assisted living) recommends ethical issues to be discussed in society:

- Should embedding of tags and sensors in the environment be regulated?
- How is the new technology launched in society?
- Are people allowed to refuse using new technologies?
- Can all citizens be provided with equal possibilities to anticipate health hazards?

The CLEAR project offers a self-assessment tool for citizen participation at the local level. It argues that participation is most successful where citizens can (have the resources, skills and knowledge), like to, are enabled to (have the opportunities), are asked to (are involved by official bodies) and responded to (see evidence that their views have been considered).⁴⁹

48 Dr. Stephen Beyer, Dr. Jonathan Perry, Andrea Meek. *A Guide to implementing Assistive Technology for people with learning disabilities*. A product of the TATE project. Welsh Centre for Learning Disabilities. School of Medicine, Cardiff University. March 2008.

49 <http://www.clearproject.co.uk>. (12.12.2010).

7. Policy strand

Ethical principles and codes are a mirror of society and the way it deals with values. In dealing with people with disabilities a fundamental shift has taken place from the **medical model** that stresses disability to a **social and human rights model** that aims at full citizenship; a paradigm shift from patient to citizen, from segregation to inclusion. This shift is clearly expressed in three of the main legislative instruments for the disability sector - the UN Convention on the Rights of Persons with Disabilities, the European Charter of Fundamental Rights, and the Council of Europe Disability Action Plan - and in initiatives of the European Commission. The shift also fits in the general rules outlined in article 13 of the EU Treaty.⁵⁰

It is interesting to analyze these instruments on the elements referring to ethical aspects on implementation and use of PCT as mentioned above.

7.1 The United Nations Convention on the Rights of Persons with Disabilities

The UN Convention asks for social inclusion of all people in society. Article 3 stipulates the norms of respect for inherent dignity, **individual autonomy** including the freedom to make one's own choices and independence of persons, non-discrimination, full and effective participation and inclusion in society, respect for difference and acceptance of persons with disabilities as part of human diversity. In article 4 (h) State Parties are invited to provide **accessible** information to persons with disabilities about assistive technologies, other forms of assistance, support services and facilities. According to article 19 people with disabilities have the right to **live independently** and to be included in the community. Persons with disabilities should have the opportunity to choose their place of residence and with whom they live on an equal basis with others, not being obliged to live in a particular living arrangement. These principles are translated in general obligations.

7.2 Europe

European identity is founded on the values contained in its Declaration for Europe. These values include respect for human beings, their freedoms, rights and dignity; the principle of solidarity and responsibility; the rule of law and equality before the law. They are non-negotiable and valid for all who reside in the Union, and they lay the foundations for a bond of trust between the Union, its different levels of governance and its citizens, and establish the key features of a common European identity.⁵¹

7.2.1 European Charter of Fundamental Rights

The main ethical values are also stated in the Charter of Fundamental Rights of the European Union and constitute the key frame for design and implementation of all EU-policies. Article 1 of the Charter states that **human dignity** is inviolable. It must be respected and protected. Article 8 is about **intrusion** by the state **into a person's private and family life**, home and correspondence, but it is framed extremely broadly and does include surveillance. Article 21 prohibits any **discrimination** on the basis of disability. Article 26 states that the EU recognizes and respects the right of persons with disabilities to benefit from measures designed to ensure their **independence**, social and occupational integration and participation in the life of the community.

7.2.2 Council of Europe Disability Action Plan

The Disability Action Plan of the Council of Europe stresses the importance of the role of AT in improving the quality of life for people with disabilities. European action will support national activities to achieve the transition from institutional to community based care.

7.2.3 European Legislation

In the former decade the European Commission forwarded directives and communications concerning protection of citizens and inclusion of people with disabilities of which several are applicable in the ethical framework:

- The Medical Services Directive (42/EEC) introduces an EC-mark ensuring that medical devices are **safe**;
- Directive 2000/78/EC offers a general framework for **equal treatment** in employment and occupation and inclusion of provision on reasonable accommodation;
- Directive 95/46/EC with regard to the **processing of personal data** and on the free movement of such data lays down a series of rights of the data subject: the right of access, of rectification, of information of all relevant details, etc. This general Data Protection Directive has been complemented by other legal instruments, such as the e-Privacy Directive for the communications sector. The right to the protection of personal data is explicitly recognized in Article 8 of the EU's Charter of Fundamental Rights and in the Lisbon Treaty (see 7.2.1.);
- The Disability Action Plan of the Commission has a strong focus on **access to Information Society by people with disabilities** and older people, as part of e-Inclusion. It became a pillar of the "i2010 – A European Information Society for growth and employment" – initiative;
- The recently adopted EU Disability Strategy 2010-2020 COM(2010) 636 final includes a section on accessibility, i.e. accessibility of information and ICT.

⁵⁰ EASPD. *Memorandum on a European Quality Principles Framework*. Brussels, December 7th 2006.

⁵¹ Deliverable D4.1 *Report on good practices, ethical guidance and designing a dialogue roadmap*. Senior Project, 2009.

8. Current international understanding of ethics and existing professional ethical codes.

8.1 International codes of professional conduct

8.1.1 RESNA Code

RESNA (Rehabilitation Engineering and Assistive Technology Society of North America), an interdisciplinary association for the advancement of rehabilitation and assistive technology, adheres to the highest standards of ethical conduct. Its members and credentialed service providers:

- Hold paramount the welfare of persons served professionally;
- Practise only in their area(s) of competence and maintain high standards;
- Maintain the confidentiality of privileged information;
- Engage in no conduct that constitutes a conflict of interest or that adversely reflects on the association and, more broadly, on professional practice;
- Seek deserved and reasonable remuneration for services;
- Inform and educate the public on rehabilitation/assistive technology and its applications;
- Issue public statements in an objective and truthful manner;
- Comply with the laws and policies that guide professional practice.

These standards are other wordings for the values and codes analysed before.

8.1.2 The Usability Professional's Association (UPA)

The Usability Professional's Association has adopted a code of professional conduct providing guidance for usability specialists in their professional practice. A Code of Conduct is available for those registered as European Ergonomists (<http://www.upassoc.org>).

8.1.3 The European Society for Opinion and Marketing Research (ESOMAR)

The European Society for Opinion and Marketing Research, together with the International Chamber of Commerce (ICC) has published ethical guidelines embodied in the ICC/ESOMAR Code of Marketing and Social Research Practice (<http://www.esomar.org>).

8.2 European approach

8.2.1 ICT that makes the difference: ESLA

Industry, R&D, European and national science policy authorities actively promote and guide the new developments in ICT which may be contributions to the economy and the quality of life but also threats. Security must be a social priority.

Therefore there is a need to analyze the ethical, socio-economic and legal aspects, the so-called ESLA of science.⁵² Indeed, ethics must not be seen as something on its own.

The European Commission wants to monitor the ESLA aspects of research by integrating the scientific resources of the Union in the European Research Area (ERA), by establishing the European Group on Ethics in Science and New Technologies (EGE) and by monitoring ethical issues in the framework programmes.

8.2.2 All European Academies (ALLEA)

Prior to the above mentioned European initiatives, ALLEA had been founded (1994) as the federation of 53 National Academies of Sciences and Humanities in 40 European countries. Next to promoting the exchange of information and experiences between academies and offering European science and society advice from its member academies the federation strives for high ethical standards in the conduct of research.

8.2.3 The European Research Area (ERA)

The European Research Area integrates the scientific resources of the European Union. Since its inception in 2000, the structure has been concentrated on multi-national co-operation in the fields of medical, environmental, industrial and socio-economic research. Its purpose is to increase the competitiveness of European research institutions by bringing them together and encouraging a more inclusive way of work promoting common social and ethical values.⁵³

8.2.4 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. The EGE members serve in a personal capacity and are asked to offer independent advice to the

52 <http://www.icthatmakesthedifference.eu>. (06.02.2011); <http://www.ICTethics.eu> (06.02.2011).

53 http://ec.europa.eu/research/era/index_en.htm (15.04.2011)

Commission. The ethical framework of the Lisbon Treaty and the European Charter, together with respect for pluralism and diversity, must be taken into account when new developments in science and technologies are to be ethically assessed.

- Effectiveness versus confidentiality:
The need to know and share patients' personal health data, in order to provide good quality care, creates a situation of shared secrecy that may compromise confidentiality;
- Privacy versus collective good:
Privacy may be traded for certain collective goods (research, administration, planning, and prevention) that benefit the community and population at large;
- Quality assurance versus professional autonomy:
Some professionals fear that quality assurance standards (protocols, clinical guidelines, clinical pathways...) may restrict or diminish professional autonomy;
- Efficiency versus beneficence:
While beneficence indicates giving the best possible care for every patient, this may be very expensive and not feasible. In a context of limited resources, giving a patient expensive care could deprive another patient of much needed basic treatment; a second best treatment may be the most appropriate in such a case.

8.3 European projects on ethics

8.3.1 Some projects

Given the relationship between ICT and society, ethics should be integrated into technical innovation. Several European projects have focused and still are focusing on the need for an ethical layer to research.

The **ICTEthics** project will analyze the development of intelligent environments and ICT for security over the next five years and **perform an integrated ESLA**.

The **EGAIS** project aims to provide **recommendations and concrete guidance on ethical governance techniques** that can be applied throughout a technical development project.

The **ETICA** project will **analyze and evaluate ethical issues** arising from emerging Information and Communication Technologies and their potential application areas. By including a variety of stakeholders and disciplinary perspectives, it will grade and **rank foreseeable ethical risks**.

8.3.2 The ETICA project

The project identifies emerging IC technologies: ambient intelligence, augmented and virtual reality, robotics and

artificial intelligence, affective computing, neuroelectronics and bioelectronics, human machine symbiosis, cloud computing and others.

It lists as arising fundamental ethical issues: privacy (given new types of data and ways of linking), data protection, intellectual property and security. As regards privacy, in particular, the important principle of proportionality must be applied, so that only information that is really necessary is generated and stored by the technology.

Ethical issues considered as less obvious are: autonomy and freedom, power relationships (self determination), responsibility and liability, access and digital divides.

The project recommends policy makers to provide a regulatory framework that will support Ethical Impact Assessment (EIA) for IC technologies to establish an ICT Ethics Observatory and a forum for stakeholder involvement.

Industry and research should incorporate ethics into ICT research and development and facilitate ethical reflexivity in ICT projects and practice.

Challenges are to design ethical review instruments responding to technological challenges, to elaborate structures and legal tools, to formulate an EU language on ethics and to balance national/supranational norms.⁵⁴

8.4 Ethics in European projects

8.4.1 Ethics in research

It is of prime importance for the EU to develop a model of responsible science funding. The Framework Programme 7 builds an ethical framework that has solid foundations: scientific and political responsibility, respect for the diversity of opinions, a search for balance of interests and respect for the principle of subsidiarity.⁵⁵ Ethical concerns must be identified and addressed by the applicants in all proposals submitted under FP7.

8.4.2 Ethical manuals in other projects

- Deliverable (D5.7.1) of the Oasis project;
- Deliverable (D.5.6.1) of the Aegis project;
- Deliverable (D4.1.) of the Senior project;
- Work package 5.6 of the Ask-it project – questionnaire-
<http://www.ask-it.org>;
- Work package 1 "Usage and ethical assessment" - Minami project;
- Work package 4 "Ethics and Human Rights" - Murinet project;
- Multidisciplinary Research Network on Health and Disability in Europe.

54 www.etica-projects.eu (11.04.2011)

55 Eleonore Pauwels. *Ethics for researchers: facilitating research excellence in FP7*. <http://www.certh.gr>. 2007.

9. User involvement

There is no **self-determination** unless users with disabilities are involved in all decisions concerning them.⁵⁶ People with disabilities, also those with intellectual disabilities can, with the right support, make choices and **express preferences about their day-to-day lives**. Involvement also means that users at least have a say about how best to spend their resources.

Is this more than theory? Are there good practices? And how have the partners of the ImPaCT in Europe project organised the feedback of users regarding the ethical framework?

9.1 Good practices

To leave the **device choice** to the user is an example of self-determination. The best way to realise this is to enable a **tryout** of the device in co-operation with the family.

9.1.1 Free choice of assistive technology

In 2007, the Swedish Institute of Assistive Technology (SIAT) coordinated the pilot study Free Choice of Assistive Technology in the county councils of Kronoberg, Stockholm and Sörmland. Following an assessment, users were entitled to a voucher to purchase the assistive devices they needed.

The pilot study shows that, within current regulation, it is possible to increase freedom of choice of assistive technology. Both Kronoberg and Stockholm have chosen to continue with the free choice. Users themselves say that Free Choice of Assistive Technology strengthens participation. They are satisfied with the information on how the assistive device functions and feel secure using it. They say that by being able to choose, the usability has increased.⁵⁷

9.1.2 Free choice of assistive technology in Europe

The free-choice solutions available in the majority of countries are complementary to the standard provision process. **Denmark** has free choice of hearing aids and it is possible to receive a voucher for specific personal assistive devices (breast prostheses, stoma products, orthopedic shoes, specially adapted wheelchairs, etc.). In **Norway**, all assistive devices can be obtained using a User pass which covers testing, the exchange of assistive device, servicing and repair, as well as advice and guidance.

In **the Netherlands**, users can get a personal budget from the municipality for wheelchairs, special bicycles and scooters, as well as for housing adaptations. In **Great**

Britain, a voucher system is in place for manual wheelchairs. Certain regions in **Italy** have introduced an assistive device budget which is a subsidy for individual assistive device programmes. In **Germany** the option of a personal budget is available.⁵⁸

9.1.3 Tryout before choice: the Tikkoteeki model of FAIDD

To be sure that the clinical suggestions are based on the opinion of correctly informed stakeholders, Tikoteekki offers computer usage assessment in **co-operation with the user's daily contact persons and a multidisciplinary team**. The assessment lasts for a period of five to six months in the close environment of the person concerned. During that time, there is a **possibility for a long tryout** period of different methods or different kinds of devices or equipment.

9.1.4 Experience of Hft

Hft have been using personalised technology (PT) with people with learning disabilities since 2004. **The person is involved** in the entire implementation process (referral, assessment, consent, response protocols, installation, review and evaluation), linking technological solutions into people's goals and aspirations, ensuring that the person has consented to the equipment being installed.

The PT Team has a specialised PT Trainer who has been providing awareness training to staff across the organisation with a very positive impact on the work.

9.2 Feedback on the ethical framework

The partners of the ImPaCT in Europe project discussed how to organise feedback from the users themselves on the designed framework. This call for feedback is a logic consequence of the fundamental principles of the study and is also a prerequisite of the project. Most partners intend to give their feedback after using the framework for some months.

9.2.1 Using Hft's questionnaire

Hft circulated a questionnaire to ask the opinion of all stakeholders on the main elements of the framework. Everyone responded. As far as involvement was concerned, all end users answered that it was their personal decision to start using PCT. Using PCT, they feel safer and this ultimately results in increased independency.

56 Dr. Stephen Beyer, Dr. Jonathan Perry, Andrea Meek. *A Guide to implementing Assistive Technology for people with learning disabilities*. A product of the TATE project, Welsh Centre for Learning Disabilities. School of Medicine, Cardiff University. March 2008.

57 Martine Estreen. *Free Choice of Assistive Technology*. Swedish Institute of Assistive Technology (SIAT), 2010.

58 Martina Estreen. *Europe with Free Choice of Assistive Technology. The provision of assistive devices in specific European countries*. Swedish Institute of Assistive Technology (SIAT), 2010.

9.2.2 Panel discussion with user organisations

End users and representatives of Inclusion Europe discussed the draft ethical framework during a meeting organised in Brussels. All participants are convinced that accessibility is the key concept to inclusion for all, with no distinction whatsoever.

It was agreed that the analysis of needs is based too often on a medical prescription. It was suggested that the European Commission be invited to ask Member States to carry out studies on discontinuance of use of devices. Since there may be a thin line between intellectual disabilities and psychological problems, the assessment should also consider possible psychological problems such as solitude. Regarding user involvement, it was stated that people with intellectual disabilities know very well what they want and must be involved in the process. Participants stated that block treatments in institutions are incompatible with personalisation and individual choices. Nevertheless people with disabilities should be considered as consumers. This fits with the use of personal budgets being promoted in several European countries. It is therefore necessary to centralise information on devices at a European level.

Concerning the loss of social contact and cognitive decline PCT can cause, participants added that PCT also creates opportunities, such as offering information on accessible places which can work as a stimulant to social contact.

In order to raise knowledge on PCT and involve end users it would be interesting to influence engineers, designers, etc. in the course of their education. Participants also underlined the effectiveness of the Universal Design concept that makes accessibility much cheaper. It is agreed that in that stage stigmatisation must be tackled.

Participants to this meeting stated that the framework addresses a lot of questions and will be a good tool to be used by professionals who perhaps need to be invited to use it. This is why it may be interesting to distribute the framework also to the Ministries for Equal Opportunities in the respective Member States. The national self-advocacy organisations are best placed to promote the framework.

10. Checklist

10.1 How to organise an ethical review?

Palm and Hansson hold the opinion that the primary task of an ethical technology assessment should be to **identify ethical issues** associated with new technology. Even if new technology often gives rise to new moral issues, historical experience can help to identify common problem areas.⁵⁹ The recommended ethical approach requires transparency and should allow for a review of any decision. Indeed, the impact of technology is difficult to predict and early interventions may enable anticipation of positive and negative impacts. Keywords are timely intervention, early communication and reporting.

Ethical guidance need not necessarily be provided in a document on its own but can also be **embedded in more general standards documents** with an administrative, clinical or technical focus.

A possible method of ethical review is hiring ethical **peer reviewers** to perform what can be called continuous ethical review continuously interviewing users in order to monitor how they perceive their participation. They can be integrated into the daily work processes relating to planning and implementing user requirements elicitation.

10.2 Use of a checklist

A **checklist** seems to be an appropriate tool. It can never guarantee that all ethical issues will be identified but can however make sure that ethical issues that are foreseeable are being identified.⁶⁰

However, checklists when used in too formalistic a way may promote ethical compliance instead of ethical sensitivity.

In the European project ASTRID **ethical practice** is not considered as a “recipe for knowledge” but as **asking questions and making choices about dilemmas** that can arise in considering what is appropriate for people with dementia. It can be assumed that the same ethical dilemmas arise in care for all other types of disability as well.

Following Rest’s (1986) **four-component model of ethical action**, perhaps the most widely accepted model in psychology, every ethical question should be composed of ethical **awareness** (interpreting the situation imagining the cause-effect chain), ethical **judgment** (which action would be most justifiable?), ethical **intention** (taking personal responsibility for moral outcomes) and ethical **behaviour** (implementing subroutines that serve a moral goal).

10.3 Structure of the checklist

In the former chapters ethical risks and codes have been treated following the implementation process. The Welsh Centre for Learning Disability used for their ethical framework the (same) chronological **process of implementation** dividing it in two main fields, pre- and post-installation.

The checklist is a non-exhaustive list of questions about ethical risks. The user (carer) can add (or eliminate) questions depending on the specific context. In fact, the list is based on fundamental questions to be answered by carers before installing assisted living technology about the benefit, the risks, the limitations, etc.

As the **basic ethical values** of autonomy, beneficence, non-maleficence and justice are valid in all stages of this process, they will be treated first before the ethical codes specific for the consecutive stages of the process.

Judgment needs **indicators**, which can be subjective, objective and organisational. Subjective indicators focus on personal rating of satisfaction and guarantee the direct participation of people with disabilities. Objective indicators (standards) can be compared between different groups and over different periods of time. Organisational indicators concern managerial aspects.⁶¹ Where possible, indicators will be added to make the ethical issues transparent.

The listed questions have been gathered from different sources of which the most important are the Welsh Centre for Learning Disabilities and the Ethical Guidance from the Senior Report.

10.4 Questions on the principal ethical values

10.4.1 Self-determination or autonomy

Indicators: independence of living – opportunity to make choices in daily life.

Main questions:

- Is the PCT used to constrain the user or to curtail her/his freedom of movement?
- Does the PCT facilitate the self-expression of the user?
- Can the user make her/his own choices and express preferences?
- Has the user a say or does she/he decide?

59 The case for ethical technology assessment, *Technological Forecasting & Social Change*, Vol. 73, 2006, pp. 543-558.

60 Anke Van Gorp. *Ethics in and during technological research. An addition to IT ethics and Science Ethics*, in Paul Sollie and Marcus Düwell: *Evaluating New Technologies*, Springer Science, Dordrecht, 2009, pp 39-40.

61 EASPD. *Memorandum on a European Quality Principles Framework*. Brussels, December 7th 2006.

Kendrick (2004) has made a scale distinguishing 6 levels of "say" starting from "no say at all" to "complete say". This scale can be used as a tool for the assessment of self-determination.

1. The user has no real influence on decisions. The organisation takes the responsibility for the whole life of the user;
2. The user has no "part" in decision-making but is informed about the decisions taken for him;
3. The person involved used to be asked for advice but the organisation decides;
4. Most of the decisions are taken by the organisation but the user has a voice in a growing number of decisions;
5. The user has a decisive voice in the majority of decisions about her/his life;
6. The user takes all essential decisions in her/his life.⁶²

10.4.2 Beneficence

Indicators: benefits of PCT.

Main questions:

- Will the PCT provide benefits for the user?
- Is the user interested in using PCT?
- Are there alternative, less privacy intrusive or less costly means of achieving the objectives of the service provision?

10.4.3 Non-maleficence

Indicators: safety, privacy.

Main questions:

- Will the PCT device(s) cause any physical or psychological harm to users?
- Have you, as service provider, consulted studies?
- Does the project affect consumer protection?

10.4.4 Justice

Indicators: equality of rights, (equal) access to all services, affordability.

Main questions:

- Has the organisation done all that's possible to reach out to the e-excluded?
- Does PCT confer benefits on some groups but not on others?
- Do some groups have to pay more than other groups?

10.4.5 Informed consent

Indicator: has the service provider obtained informed consent of those persons involved in or affected by the service?

Main questions:

- Has the person been informed of the nature, purpose, significance, implications and risks of the proposed device?
- If the user is not able to give informed consent to use a technology, has the carer consulted with relatives or obtained written consent from the user's legal representative?
- Has the capacity of the user been ascertained?

The U.K. Estia centre (<http://www.estiacentre.org>) has established an objective method for assessing (intellectual) capacity in 4 stages:

- Does the assessed person understand and retain the information relating to the decision?
- Does she/he believe the information, and can she/he repeat it?
- Is she/he able to weigh that information in the balance to arrive at a choice?
- Can she/he communicate the decision?

The TATE project's policy was that:

- All co-residents needed to consent to equipment that all would need to use;
- Devices that one person would use required only individual consent;
- Basic systems that were fully justified under health and safety and duty of care were installed without the possibility of veto (e.g. smoke sensors);
- The accommodation owner needs to be made aware of the proposed AT, the implications for the fabric of their accommodation and give written consent for the work;
- When giving consent, does the user understand the consequences?

10.5 Questions for every stage in the implementation process

10.5.1 Assessment of needs and preferences of the user

Indicator: structural method to assess the needs.

Main questions:

- Is the assessment based on medical prescription or on functional needs?
- Are abilities (digital literacy) also assessed and preferences asked?
- Has the assessment been done by a multidisciplinary team?
- Is attention given to the evolution of the disability and expectations of the user?

62 M. Kendrick. *Discerning Actual levels Of Substantive Empowerment*. Paper, Kendrick Consulting International. 2004

- Is a feedback procedure established during the use of PCT?
- Are aspects such as acceptance of the disability and self-confidence taken into account?
- Is the assessment executed in the (social) environment, in collaboration with the social network?
- How is PCT integrated in the care plan, how is utilisation of PCT planned, for which functions?
- Is it made accountable to the social network? How?
- Does the user have a say? To what level has the user organised her/his life for her/him? Is there a personal future planning with outcomes to be achieved?

10.5.2 Selection of the most adequate PCT device on the market

10.5.2.1 Knowledge of the market of PCT

Indicators: information sources available, training sessions organised.

Main questions:

- How is knowledge built up in the organisation? How many carers are involved?
- Is the needed device available on the (national) market? Are there several sellers?
- Is it accessible (physical, economic, information)?
- Is it affordable (in terms of money, time, energy)? Have funding streams for purchase and maintenance been identified?
- Which accommodation does it need? Interoperability? Arrangements for installation?
- Is it appropriate? How is it tested?
- Is the information objective, independent (non commercial)?
- Is the information (made) accessible for the user (e.g. pictures)?

10.5.2.2 User involvement in decision making

Indicators: meetings with user.

Main questions:

- Who takes the decision: the user, the family, the carer?
- Is a demo organised, is a try-out possible?
- Does the service require users to use a technology that marks them in some way?

10.5.3 Implementation and use of PCT in care

10.5.3.1 Care plan

Indicators: governance policy, written care plan, complaint procedures.

Main questions:

- Is the care plan built up gradually, starting with the least radical intervention?
- Has the care been personalised? Is the organisation tailor-made, adapted to give room for individual choices, and if so, how?

10.5.3.2 Enablement and empowerment of users

Indicators: training for users, assessment of abilities.

Main questions:

- Does PCT empower the user? Does the care plan empower the user sufficiently?
- Is the user aware of what the system is doing and why?
- Does the user know how to control the system in different usage situations?
- Will training be provided on computer skills but also on life skills?
- How is competence building for carers organised?

10.5.3.3 Privacy

Indicators: procedures for data protection, data transport, digital access codes.

Main questions:

- Can information be used in such a way as to cause unwarranted harm or disadvantage to the user?
- Data collection: how will it be determined what constitutes the minimum amount of information? What will be collected and why?
- Is behaviour monitored?
- How are personal data protected?
- To whom is access to personal data allowed, on which conditions?
- What are the rules for storage and interchange of personal data?

10.5.3.4 Risk management

Indicators: safety procedures, operating standards, maintenance programme.

Main questions:

- Have risks been balanced to abilities?
- Has equipment been evaluated on reliability?
- What happens when the technology fails?
- Who is alerted when a sensor is activated? What action is required?
- What should happen when a user being alerted does not respond within a specified time period?

10.5.4 Assessment of effects of PCT

Indicators: written outcomes, quality standards, monitoring system, meetings with carers, number of social contacts, means of communication used by the person with disabilities.

Main questions:

- Is the efficiency of care assessed using the achievement of personal outcomes of quality of life?
- Are the staff objectives and evaluation linked to this personal care plan?
- Is the assessment made accountable to the family?
- Has the loss of personal skills been assessed? If so, how?
- Has the influence of PCT on carers' tasks been assessed, on transfer of control?
- To what degree is independence realised?
- Is there a risk that the technology may lead to greater social isolation?
- Which means of communication does the user have at her/his disposal: digital communication (use of internet), audiovisual communication (radio and television) and oral communication (face-to-face, by phone)?
- Does the user participate at local community?
- Are initiatives taken to increase social contacts?

10.5.5 Feedback to R&D and industry to user led PCT

Indicators: contacts with R&D, actions of awareness raising, training on Universal Design.

Main questions:

- Is the usability of PCT devices (constantly) assessed?
- Are developers and industry informed?
- Is the organisation familiar with the concept of Universal Design?

10.5.6 Feedback to government and society

Indicators: contacts with policy makers, awareness raising of public opinion.

Main questions:

- Is the organisation familiar with governmental policies on disability, e-inclusion, equal opportunities, digital literacy, and so on?
- Does the organisation have a written point of view of social benefits of PCT?
- Are problems of labelling/discrimination being discussed in the organisation?

10.5.7 Transparency

Main question: are the ethical codes written out?

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