

Publishable Summary

The *ETHICAL* project vision is an international consensus on the *ETHICAL* use of personal data as a basic human right in the information society. Its mission is to be an effective mechanism for societal partners' engagement in enhancing the debate on *ETHICAL* implications of data collection, use and retention in medical and biometric applications, in order to create a consensus and a roadmap towards a secure environment and simultaneously no compromise in human rights respect.

The *ETHICAL* Coordination Action is contributing, in 24 months, to the execution of the FP7 Capacities Work Programme: Science in Society, aiming at a "Better understanding of the place of science and technology in Society for the period 2007-2013".

The *ETHICAL* project aims to contribute to these objectives by an approach of critical reflection on the deep relationships between knowledge and democracy. It coordinates an international debate, with openness, participation, accountability, transparency and effectiveness. The *ETHICAL* project has a set of concrete objectives to fulfil:

- To formulate an international dialogue on *ETHICAL* implications of data collection, use and retention in medical and biometric applications, in three specific themes. Potential data misuse, development of a unique identifier and international standardization of *ETHICAL* requirements
- To develop a guide on government – industry collaboration prerequisites concerning the data collection, use and retention in medical and biometric applications.
- To develop a code of conduct for FP7 researchers, concerning the data collection, use and retention in medical and biometric applications.
- To identify the set of *ETHICAL* requirements for international biometric and medical data sharing.
- To create synergies with SINAPSE e-community of National Ethics Councils.

As the protection of medical and biometric Data represents a topic of strategic importance in European society it has a major impact in the core of *ETHICAL* European concepts and beliefs. In real terms Security and Privacy is in the core of ICT technology advancements, by altering the landscape of services and applications, change the everyday life of European citizen affecting his/her life and its quality and his/her fundamental rights. The *ETHICAL* project with its focus in enhancing and facilitating the debate, taking into consideration the experts' and the industry's scientific views and fore-thinking, affects in a mature and careful

way the societal challenges in European era.

1.1 Description of the work performed since the beginning of the project.

The launching of the *ETHICAL* project coincided with the Consortium's effort to establish a concrete identity for the project, from its very beginning. The Consortium created the project website from month one, (www.ethical-fp7.eu) a logo and a vision document.

The scientific work carried out by the *ETHICAL* Consortium is reflected in the detailed report on the *ETHICAL* implications of data collection, use and retention. The report includes presentation of *ETHICAL* implications, analysis of cases of data misuse, and proposed recommendations for medical and biometric data collection, use, and retention.

In the Guide on Government – Industry collaborations, the ethics of data sharing between government and industry collaborators are presented. Examples of government-industry collaborations are gathered, a proposed list of checks and balances to adhere to privacy law, best practices for government-industry collaborations, and proposed recommendations for data sharing between collaborators are included.

A study on *ETHICAL* requirements for international biometric and medical data sharing is performed already. Existing laws and guidelines on data sharing, principles for *ETHICAL* data sharing, and ongoing debates are discussed. Benchmarks for privacy recognition and international privacy principles are proposed.

The *ETHICAL* project is deploying a trustworthy Common Information Platform, where all activities are presented and supported, mainly the public dialogue. The *ETHICAL* Consortium has delivered guidelines of the way the dialogue is conducted and these guidelines form a set of requirements for an effective dialogue. Furthermore, the Consortium identified the questions that should be a starting point for the debate.

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