Stakeholder-informed ethics for new technologies with high socio-economic and human rights impact

Risultati

Informazioni relative al progetto

SIENNA

ID dell'accordo di sovvenzione: 741716

Sito web del progetto 🔗

DOI
10.3030/741716 🔗

Progetto chiuso

Data della firma CE
25 Aprile 2017

Data di avvio
1 Ottobre 2017

Data di completamento
31 Marzo 2021

Finanziato da
Develop the governance for the advancement of responsible research and innovation by all stakeholders, which is sensitive to society needs and demands and promote an ethics framework for research and innovation

Costo totale
€ 3 996 787,50

Contributo UE
€ 3 996 787,50

Coordinato da
UNIVERSITEIT TWENTE
Netherlands

Questo progetto è apparso in...

CORDIS fornisce collegamenti ai risultati finali pubblici e alle pubblicazioni dei progetti ORIZZONTE.

I link ai risultati e alle pubblicazioni dei progetti del 7° PQ, così come i link ad alcuni tipi di risultati specifici come dataset e software, sono recuperati dinamicamente da .OpenAIRE.

Risultati finali

Documents, reports (35) ⌄

Ethical assessment of human enhancement

A review of existing ethical theories and approaches regarding human enhancement and an ethical impact assessment of current and future ethical issues, both regarding human enhancement in general and in relation to specific technologies, domains and applications.

Report of the human enhancement citizen panels

A report of the discussions and outcomes of panels of citizens in five EU countries on the social and ethical issues raised by human enhancement.

Methodology to help public research funding organisations reconcile the views and interests of scientists and citizens

This report will outline a general methodology that could be used by public research funding organisations and similar organizations to help reconcile the needs of scientific researchers and the legitimate concerns of citizens

Ethical assessment of HMI

A review of existing ethical theories and approaches regarding human-machine interaction technologies and an ethical impact assessment of current and future ethical issues, both regarding human-machine interaction technologies in general and in relation to specific technologies, domains and applications.

[Proposal for an ethical framework for genomics](#) 🔗

An ethical framework for the assessment of genomics technologies that takes into account the views and judgements of ethicists, scientists, CSOs and citizens.

[Report of the HMI citizen panels](#) 🔗

A report of the discussions and outcomes of panels of citizens in five EU countries on the social and ethical issues raised by human-machine interaction technologies.

[Methods for translating ethical analysis into instruments for the ethical development and deployment of emerging technologies](#) 🔗

A report documenting generalized methods for developing codes and operational guidelines, ethics by Design approaches, policy guidance, guidance documents for research ethics committees and other methods in support of the ethical development and deployment of emerging technologies

[Survey of REC approaches and codes for HMI (Formerly EUREC)](#) 🔗

A survey report that determines for research ethics protocols and professional ethics codes in different EU countries and internationally to what extent and how they refer explicitly or implicitly to genomics technologies, and that surveys the opinions of representatives of research ethics committees to determine awareness of these technologies and the approach that they take and would like to take to them.

[Report of the HMI societal acceptance and awareness surveys](#) 🔗

A report with results and analysis of telephone surveys in 11 countries to assess the level of societal acceptance and awareness of human-machine interaction technologies.

[Analysis of legal and human rights requirements for human enhancement in and outside the EU](#) 🔗

A report documenting and critically assessing the legal, including human rights, requirements applicable to human enhancement, including an analysis of EU and international norms and regional legal orders, an analysis of human rights norms and ways in which human rights may be affected by human enhancement technologies, and an analysis of national laws in comparison to international and regional norms and human rights standards.

[Report of the genomics societal acceptance and awareness surveys](#) 🔗

A report with results and analysis of telephone surveys in 11 countries to assess the level of societal acceptance and awareness of genomics technologies.

[Interim report on communications](#) 🔗

An interim report on outreach measurements as defined in the communication and dissemination plan.

[Report on adapting methods for ethical analysis of emerging technologies](#) ↗

A report that generalizes from the ethical methods developed and used in WPs1, 2, 3 and 4 to arrive at general methods for the ethical analysis of emerging technologies, with special attention to the incorporation of stakeholder consultation into ethical analysis and to the integration of ethical impact assessments with social and economic impact assessments, human rights assessments, and legal analysis..

[Analysis of the legal and human rights requirements for HMI in and outside the EU](#) ↗

A report documenting and critically assessing the legal, including human rights, requirements applicable to human-machine interaction, including an analysis of EU and international norms and regional legal orders, an analysis of human rights norms and ways in which human rights may be affected by human-machine interaction technologies, and an analysis of national laws in comparison to international and regional norms and human rights standards.

[Ethical assessment of genomics](#) ↗

A review of existing ethical theories and approaches regarding genomics technologies and an ethical impact assessment of current and future ethical issues, both regarding genomics in general and in relation to specific technologies, domains and applications.

[State of the art review of genomics](#) ↗

Report of the state of the art of genomics, including a demarcation and brief history of the field, the basic scientific and commercial developments, and their present and anticipated social and economic impacts.

[State-of-the-art review of human machine interactions](#) ↗

Report of the state of the art of human machine interaction, including a demarcation and brief history of the field, the basic scientific and commercial developments, and their present and anticipated social and economic impacts.

[Report of the Genomics citizen panels](#) ↗

A report of the discussions and outcomes of panels of citizens in five EU countries on the social and ethical issues raised by genomics technologies.

[Recommendations for the enhancement of the existing EU and international legal framework](#) ↗

A report with recommendations for the enhancement of the existing EU and international legal framework, especially in relation to the three investigated technologies.

[Report on adapting methods for legal analysis of emerging technologies](#) ↗

A report analyzing the possibilities for the general application of our approach for legal and human rights analysis, with reference to other types of future and

emerging technologies, and outlining a refined methodology, elaborating and adapting the approach developed in Task 1.2.

[Proposal for an ethical framework for human enhancement](#) ↗

An ethical framework for the assessment of human enhancement technologies that takes into account the views and judgements of ethicists, scientists, CSOs and citizens.

[The consortium's methodological handbook (outlining its detailed approach)](#) ↗

An handbook documenting the SIENNA approaches for ethical analysis, legal and human rights analysis, the study of societal acceptance and awareness, stakeholder analysis and public engagement approach, and the analysis and development of research ethics protocols and professional ethical codes (tasks 1.1 through 1.5), as well as their benefits, limitations and challenges.

[Sustainability plan: options and strategies for promoting the project's legacy](#) ↗

This report will identify and explore the various options and strategies for promoting beyond the project's timespan the project's codes of conduct, other research outputs and networks developed during the project's stakeholder engagement activities.

[Proposal for an ethical framework for HMI](#) ↗

An ethical framework for the assessment of machine-interaction technologies that takes into account the views and judgements of ethicists, scientists, CSOs and citizens.

[Central elements of a code of responsible conduct for researchers in genomics](#) ↗

A report with a proposal for central elements in a code of responsible conduct for researchers in genomics.

[Methods for promoting ethics in human enhancement](#) ↗

A report with a proposal for ethical guidelines for human enhancement, as well as other proposals for supporting the ethical development and deployment of human enhancement technologies

[Report documenting elements to open and complement operational guidelines for research ethics committees](#) ↗

A report that examines the scope of existing operational guidelines for research ethics committees in the biomedical field and demonstrates how these operational guidelines could be extended to other research areas.

[Survey of REC approaches and codes for human enhancement (Formerly EUREC)](#) ↗

A survey report that determines for research ethics protocols and professional ethics codes in different EU countries and internationally to what extent and how

they refer explicitly or implicitly to human enhancement , and that surveys the opinions of representatives of research ethics committees to determine awareness of these technologies and the approach that they take and would like to take to them.

[Survey of REC approaches and codes for genomics ↗](#)

A survey report that determines for research ethics protocols and professional ethics codes in different EU countries and internationally to what extent and how they refer explicitly or implicitly to genomics technologies, and that surveys the opinions of representatives of research ethics committees to determine awareness of these technologies and the approach that they take and would like to take to them.

[Multi-stakeholder strategy and practical tools for ethical AI and robotics ↗](#)

A report with a multistakeholder strategy for ethical AI and robotics, including proposals for practical tools for supporting ethics, including, but not limited to, a research ethics framework, an Ethics by Design approach, proposals for ethics education, training and awareness raising, a proposal for humanities and social sciences research to supplement AI ethics, as well as other proposals for supporting the ethical development and deployment of human enhancement technologies

[Final report on communications ↗](#)

A final report on outreach measurements as defined in the communication and dissemination plan.

[Report of the human enhancement societal acceptance and awareness surveys ↗](#)

A report with results and analysis of telephone surveys in 11 countries to assess the level of societal acceptance and awareness of human enhancement.

[State-of-the-art review of human enhancement ↗](#)

Report of the state of the art of human enhancement, including a demarcation and brief history of the field, the basic scientific and commercial developments, and their present and anticipated social and economic impacts.

[Analysis of the legal and human rights requirements for genomics in and outside the EU ↗](#)

A report documenting and critically assessing the legal, including human rights, requirements applicable to genomics, including an analysis of EU and international norms and regional legal orders, an analysis of human rights norms and ways in which human rights may be affected by genomics technologies, and an analysis of national laws in comparison to international and regional norms and human rights standards.

[Communication and dissemination plan ↗](#)

A report that outlines a communication and dissemination strategy and includes an activity plan for the first 12 months. This plan will be updated regularly.

Websites, patent fillings, videos etc. (2) ⌄

[Press release ↗](#)
A global press-release, to be issued by UT, followed by local releases from other partners.

[Website launch ↗](#)
Delivery of a website for SIENNA.

Pubblicazioni

Peer reviewed articles (8) ⌄

[Germline Genome Editing Research: What Are Gamete Donors (Not) Informed About in Consent Forms? ↗](#)
Autori: Emilia Niemiec, Heidi Carmen Howard
Pubblicato in: The CRISPR Journal, Numero 3/1, 2020, Pagina/e 52-63, ISSN 2573-1599
Editore: Mary Ann Liebert, Inc., publishers
DOI: 10.1089/crispr.2019.0043

[Ethical issues related to research on genome editing in human embryos ↗](#)
Autori: Emilia Niemiec, Heidi Carmen Howard
Pubblicato in: Computational and Structural Biotechnology Journal, Numero 18, 2020, Pagina/e 887-896, ISSN 2001-0370
Editore: Elsevier
DOI: 10.1016/j.csbj.2020.03.014

[Transparency, consent and trust in the use of customers' data by an online genetic testing company: an Exploratory survey among 23andMe users ↗](#)
Autori: Aviad E. Raz, Emilia Niemiec, Heidi C. Howard, Sigrid Sterckx, Julian Cockbain, Barbara Prainsack
Pubblicato in: New Genetics and Society, Numero 39/4, 2020, Pagina/e 459-482, ISSN 1463-6778

Ethics as attention to context: recommendations for the ethics of artificial intelligence ⧉
Autori: Anais Resseguier, Rowena Rodrigues

Legal and human rights issues of AI: Gaps, challenges and vulnerabilities ⧉
Autori: Rowena Rodrigues

The Ethics of Genetic Cognitive Enhancement: Gene Editing or Embryo Selection? ⧉
Autori: Marcelo de Araujo

AI ethics should not remain toothless! A call to bring back the teeth of ethics ⧉
Autori: Anaïs Rességuier, Rowena Rodrigues

THE RIGHT TO SCIENCE AND HUMAN GERMLINE EDITING. Sweden, its external commitments and the ambiguous national responses under the Genetic Integrity Act
Autori: Santa Slokenberga and Heidi Carmen Howard

Book chapters (1) ⌄

"Genethics" and Public Health Genomics ⧉
Autori: Emilia Niemiec, Heidi Carmen Howard
Pubblicato in: Applied Genomics and Public Health, Numero [ed] George P.

Non-peer reviewed articles (2)

The Greek Law on Genetics and Genomics - An Overview and Outlook for Future Perspectives ⧉
Autori: Maria Canellopoulou-Bottis
Pubblicato in: SSRN Electronic Journal, Numero Posted 22 Dec 2018, 2018, Pagina/e 1-20, ISSN 1556-5068
Editore: ELSEVIER
DOI: 10.2139/ssrn.3295632

Setting future ethical standards for ICT, Big Data, AI and robotics ⧉
Autori: Josepine Fernow, Inigo De Miguel Beriain, Philip Brey, Bernd Stahl
Pubblicato in: ORBIT Journal, Numero 2019/1, 2019, Pagina/e 1-8, ISSN 2515-8562
Editore: Orbit
DOI: 10.29297/orbit.v2019i1.115

Altri prodotti di ricerca

Altri prodotti di ricerca tramite OpenAire (18)

Enhancing EU legal frameworks for genetics & genomics research SIENNA project Policy Brief #2 ⧉
Autori: Santa Slokenberga
Pubblicato in: Zenodo

SIENNA infographic: Human enhancement ⧉
Autori: University of Twente; Centre for Research Ethics & Bioethics, Uppsala University
Pubblicato in: Zenodo

Inteligencia artificial y robótica. Cómo mejorar el marco legal en España ⧉
Autori: Prieto, Javier Valls
Pubblicato in: Zenodo

[Βελτιώνοντας το ευρωπαϊκό νομικό πλαίσιο για την έρευνα στη γενετική και τη γονιδιωματική-Σύνοψη πολιτικής του προγράμματος SIENNA αρ. 2 ⬏](#)
Autori: Slokenberga, Santa
Pubblicato in: Zenodo

[Promoting ethics for human enhancement technologies: SIENNA project Policy Brief #5 ⬏](#)
Autori: Erden, Yasemin J.; Brey, Philip
Pubblicato in: Zenodo

[Genética y genómica humana. Mejora del marco jurídico de España ⬏](#)
Autori: Javier Valls Prieto
Pubblicato in: Zenodo

[Enhancing EU legal frameworks for AI & robotics: SIENNA project Policy Brief #1 ⬏](#)
Autori: Trilateral Research
Pubblicato in: Zenodo

[SIENNA infographic: AI & ROBOTICS ⬏](#)
Autori: Trilateral Research; Centre for Research Ethics & Bioethics, Uppsala University
Pubblicato in: Zenodo

[Ηθική, δεοντολογία και ανθρώπινα δικαιώματα για τις νέες και επερχόμενες τεχνολογίες: Σύνοψη πολιτικής του προγράμματος SIENNA αρ. 4 ⬏](#)
Autori: SIENNA project
Pubblicato in: Zenodo

[Ethics & human rights for new and emerging technologies: SIENNA project Policy Brief #4 ⬏](#)
Autori: SIENNA Project
Pubblicato in: Zenodo

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Permalink: https://cordis.europa.eu/project/id/741716/results/it

European Union, 2025