

EUROPEAN
CURRICULUM VITAE
FORMAT



PERSONAL INFORMATION

Name	SARA CASATI
SCOPUS and relevant links	http://it.linkedin.com/pub/sara-casati/26/a74/126/ m
E-mail	
Nationality	Italian
Gender	

Bioethicist by training but a practical philosopher by imprinting, very fond of participatory approaches & deliberative methods. From the very beginning of my career, I understood bioethics as a democratization of science practice, as well as science as a responsible and open process working for innovative and inclusive governance. With enthusiasm I face the challenge to accordingly rethinking training models regarding multi-actor empowerment and engagement and framing research within a Responsible Research & Innovation - RRI Horizon.

In the last 25 years, as a senior bioethicist, Ethical-Legal-Societal trainer, and consultant for both private and public organizations, I have been promoting and coordinating at national and international levels participatory, multidisciplinary actions both in science and medicine fields involving the diverse actors at stake, besides recognizing patients and citizens as partners. Some pioneering contexts have been vital training grounds for my professional and methodological path. I was on the front line with the Rare Disease community for the Stamina affair, the Beta-Thalassemia community coediting the informed consent to the GLOBE Genetic “Therapy” 1st Phase Trial, and the Translational Medicine Hospitals, the IRCCS. Moreover, I learnt much working in the field with many special vulnerable groups such as African immigrant women to step forward infibulation, soldiers in Cyprus to mitigate potential abuses in sample-and-data-based research and children as participants in the research processes.

As a member of many Research Ethics Committees (Comitato Etico di AOU Verona; Comitato Etico Area Vasta Nord – Emilia Romagna; Comitato Etico Regionale Sezione A – Emilia Romagna, Comitato Etico Regione Toscana - pediatrico), **Institutional Review Boards/University Ethics Committees**(Milano-Bicocca University Research Ethics Committee, Patients with Neuromuscular Diseases Registry Ethical Committee - Milan), **Advisory Boards** (E-Rare Advisory Board; EURORDIS Experts Panel; European Joint Programme on Rare Diseases – EJP-RD Advisory Regulatory Ethics Board-AREB, Registro della Malattia Esostomane - REM Advisory Board, IOR - Bologna) **as well as President of Milano-Bicocca University Research University Ethics Committee I have been having a privileged observatory on frontiers issues of Advanced Research & Scientific Ethics.**

My expertise in creating and ensuring both participatory settings and Ethical-legal-social-issues/implications - ELSI good practices, with the ability to network and facilitate institutional mediation, was thus consolidated. My interlocutors and partners are certainly patients, researchers, clinicians, DPOs, Research Ethics Committees, Research Institutions, etc., but at the same time constantly policymakers, regulatory and privacy authorities, research bodies, and ministries.

This journey highlighted the need for an inclusive, pluralist, and responsible scientific environment.

My trace led me to the ESFRI world, where I found a natural fit in the Biobanking and Biomolecular Resources Research Infrastructures - BBMRI. Here, I took on the challenge of building a Common Service - CS ELSI and enhancing translational

biobanking integrated with healthcare. Since joining the ESFRI world in 2011, I have played a key role in establishing the national node and the CS ELSI at the European level, furthering my commitment to infrastructure research processes and governance.

For the past ten years, I have been part as an **expert bioethicist of the ELSI Services & Research Unit** at the Head Quarter of BBMRI-ERIC while **coordinating ELSI and ELSI Help-desk activities at the national level for BBMRI.it**.

In parallel for the last five years, **I have been coordinating the InfraUNIMIB Service and the Responsible Research & Innovation-RRI Institutional Activities & communities of practices for Milano-Bicocca University**.

Since July 2013, I have been **responsible for the ELSI and RRI activities of the PNRR—Strengthening BBMRI Project for the CNR**.

WORK EXPERIENCE

- Dates (from - to) July 2023 - *ongoing*
 - Name and address of the employer CNR – IEOS, Naples, Italy
 - Type of business or sector EU Research Infrastructures – ESFRI - PNRR
 - Occupation or position held **Senior Technologist – ELSI Manager**
 - Main activities and responsibilities *Digitalization of the ELSI Common Service through a systemic community action aimed at co-creating:*
 - ✓ *an ELSI/RRI knowledge base platform,*
 - ✓ *a community of Practices of platform,*
 - ✓ *a digital informed assent/consent to biobank-based-research based on the APP BIOBANK (under construction)*
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- Dates (from - to) July 2023- *ongoing*
 - Name and address of the employer Comitato Etico Regione Toscana - Pediatrico
 - Type of business or sector Ethics review, Clinical Trials, Clinical studies
 - Occupation or position held *Vicepresident*
 - Main activities and responsibilities *Bioethics expert, next generation biobanking expert*
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- Dates (from - to) 2011 – *ongoing*
 - Name and address of the employer Università degli studi di Milano-Bicocca, Milan (Italy)
 - Type of business or sector **University Research Committee**
 - Occupation or position held **Senior Bioethicist; President (till 2018), member till today**
 - Main activities and responsibilities
 - ✓ Ethics reviewing
 - ✓ Development and sharing of research University Policies
 - ✓ ELSI support & training
 - ✓ Research integrity and ELSI challenges in science
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- Dates (from - to) 2014 – *ongoing*
 - Name and address of the employer **BBMRI.it – National Node of the Biobanking & Biomolecular Resources Research Infrastructure**, Milano/Roma (Italy)
 - Type of business or sector EU Research Infrastructure ESFRI - ELSI Service and Training
 - Occupation or position held **Senior Bioethicist leading both the BBMRI.it ELSI service and the ELSI helpdesk**
 - Main activities and responsibilities
 - ✓ **Responsible for the National ELSI helpdesk.**
 - ✓ Ideation and lead of the **ELSI national working groups as community engagement processes based in participatory approaches.**
(2022 – “Institutional biobanking of old collection”; 2021 – “For good practice in translational biobanking”; 2020 – “ELSI4Covid”; 2019 – “Access & sharing: From data to results”; 2018 – 2017 “Towards a good practice in biobank-based research”; For a good practice in ethics review in biobank-based research”).
 - ✓ **Together with the biobanking community included Patient/Citizen representatives, co-design and lead of ELSI tools** (informed consent matrix; ethics review matrix; MTA matrix, etc.).
 - ✓ Drafting and editing **national guidelines in translational medicine**, position statements on ELSI challenges in translational(research) biobanking.
 - ✓ Ensure diverse **training activity portfolio** (webinars, workshops, podcasts, etc.) based on both **empowerment and deliberative methods.**

- Dates (from - to)
- Name and address of the employer
- Type of business or sector
- Occupation or position held
- Main activities and responsibilities

- ✓ **Outreach, Public information, multi-actor Engagement initiatives** such as “Biobanking is about me” and “Open doors in biobanks” during the Global/EU Biotech Weeks.

Currently coordinating the community bbbmri.it action towards the Privacy Authority and under the Healthcare National Institute lead, drafting the “Recommendations for the secondary use of biological materials of clinical origin” in dialogue with the REC National Commission and the Privacy Authority.

2014 – ongoing (as senior bioethicist of the BBMRI ERIC ELSI Federated Network)

Biobanking & Biomolecular Resources Research Infrastructure – BBMRI European Research Infrastructure Consortium – ERIC, Graz, Austria

European Research Infrastructure ESFRI – ELSI Services & Research Unit

Bioethicist; Research Ethics Committees - REC Expert Group (Past Task Force REC); Paediatric activities coordinator

- ✓ Leading the **BBMRI-ERIC Expert Group Research Ethics Committees** (past BBMRI-ERIC Task Force REC) and the **Mapping European Research Ethics Committees - RECs & Ethics review processes for biobank-based research.**
- ✓ ELSI member of
 - AREB (EJP-RD)
 - EU ELSI Helpdesk
 - EU Federated ELSI Network
- ✓ Scientific Responsible and coordinator for the stage **“Paediatric (research) biobanking and minor engagement” of the EBW22 Roadshow.**
- ✓ Together with the Stakeholder Forum Patient and Citizen Pillar, design and chair of both the BBMRI ERIC ELSI Paediatric Action and the related community of practice.
- ✓ **ELSI Task lead in EU Projects** such as EPTRI, EJP-RD, CY-Biobank.
- ✓ Facilitating and **supporting RD biobanks to test the Common Conditions of Use/Access (DUC profile) to introduce metadata both at resource and record level.**
- ✓ **Providing expertise on ELSI aspects in:**
 - healthcare integrated/translational/AI-supported biobanking, with special attention to vulnerable populations/individuals,
 - informed consent/assent as a participatory process,
 - ethical review in samples & data-based research.
- ✓ **Advising on Responsible Research & Innovation - RRI, citizen science and engagement processes** with a specific focus on rare diseases and biobanking with children.
- ✓ Improve and/or update the **ELSI Knowledge Base** contents.
- ✓ EU CanServ/Project/Proposal EU **ethics check.**
- ✓ Involved in leadership positions in the Task Force Societal and Success Stories (concluded)

- Dates (from - to)
- Name and address of the employer
- Type of business or sector
- Occupation or position held
- Main activities and responsibilities

2021 - ongoing

Regione Emilia-Romagna (Italy)

Regional Research Ethics Committee

Bioethicist, Coordinator of the Biobank group

- ✓ Ideation and coordination of innovative hands-on ELSI programmes involving the joint training of committees, researchers, research support services, biobankers.
- ✓ Support to research ethics committees.
- ✓ Drafting and editing ELSI policies in clinical trials, sample-and-data-based studies (prospective and retrospective), patient/volunteer engagement in research.

- Dates (from - to)
 - Name and address of the employer
 - Type of business or sector
 - Occupation or position held
 - Main activities and responsibilities
- 2017 – April 2023
Università degli Studi di Milano-Bicocca, Research Area, Rectorate, Milano (Italy)
- Research & Education. Ethical-Legal-Social-Issues - **ELSI**; Responsible Research & Innovation - **RRI**; Research Infrastructure - **ESFRI**
- Technologist, RRI Coordinator & ELSI specialist**
- ✓ **Ideation & Establishment of INFRAUnimib**, a tailored university service to improve Research Infrastructure ESFRI culture and partnership within the different scientific communities with special attention to the younger generation.
 - ✓ **Activation & coordination of both a structured RRI service and Hands-on RRI training programmes** for PhD students, researchers, and technologists, envisioning a RRI community of practices, including Citizen/School Umbrella organizations.
 - ✓ **Design & coordination of Participatory research, Citizen science, scientific citizenship, and multi-actor engagement** initiatives (projects, labs, debates, etc.)
 - ✓ ELSI Task Lead in EU projects such as Instand-NGS4P (curation of deliverables on dynamic informed consent matrix, minor’s assent matrix, “incidental”-secondary results in NGS), Skills4EOSC, RitrainPlus, etc.
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- Dates (from - to)
 - Name and address of the employer
 - Type of business or sector
 - Occupation or position held
 - Main activities and responsibilities
- 2015 – 2017
 Ordine dei medici Odontoiatrici di Reggio in Emilia
 Reggio in Emilia
- Professional Organization, Deontology, and medical ethics
- Project head, Trainer, Bioethicist**
- Design, programming, and development of the empowerment program **CLINICAL BIOETHICS OFFICINE** - a two-year initiative
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- Dates (from - to)
 - Name and address of the employer
 - Type of business or sector
 - Occupation or position held
 - Main activities and responsibilities
- 2014 – 2015
 Telethon Foundation onlus
 Piazza Cavour 1, 20121 Milano
- Charity, **Advanced Research, Rare Diseases**
- Project head, Trainer**
- ✓ Scientific development and coordination National quality-of-life matrix mapping for the person experiencing rare disease and/or an intellectual/physical disability
 - ✓ In-depth interviews with national association leaders
 - ✓ Socratic dialogues with patients and caregivers
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- Dates (from - to)
 - Name and address of the employer
 - Type of business or sector
 - Occupation or position held
 - Main activities and responsibilities
- 2013 – 2022
 ASL della Romagna
- Healthcare, Clinical Governance, Clinical research
- Clinical Bioethicist, Trainer, Governance consultant**
- ✓ Planning, coordination and development of training activities based in participatory methods and modeling of best practices among which
 - “Per una buona pratica della sicurezza del paziente in sala operatoria”
 - “Promozione della salute sessuale e riproduttiva delle donne straniere, quale strumento di prevenzione primaria delle mutilazioni genitali femminili (MGF)”
 - “Tracciare, documentare, informare: la cartella clinica come strumento di buona pratica in equipe”
 - “In che consiste essere coordinatore in un contesto organizzativo complesso”

- Dates (from - to)
 - Name and address of the employer
 - Type of business or sector
 - Occupation or position held
 - Main activities and responsibilities
- 2011 – July 2013
 Bionsil S.r.l., Monza (Italy)
- Academic spin-off, basic cancer research**
- Bioethicist, Project manager**
- ✓ ELSI support
 - ✓ Research Governance of clinical studies
 - ✓ Management of relations between the Investment Fund, the University, and the different bodies involved in research activities.
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- Dates (from - to)
 - Name and address of the employer
 - Type of business or sector
 - Occupation or position held
 - Main activities and responsibilities
- 2010 – 2021
 Uniamo F.I.M.R., Roma (Italy)
- Third section association; RD Advanced research & Innovation; Tailored caring & assistance**
- Bioethicist consultant; Coordinator of Rare Disease - RD national working groups & project head; Creator of participatory public events on translational medicine, research, and ELSI challenges; trainer.**
- ✓ Design, development, and coordination of multi-actor national projects including Regions, Ministry Directorates, Scientific Societies, Registries, Biobanks, patient Organizations.
 - ✓ Ideation of a National Roadmap and coordination of National Play-decide debates on RD challenges with the extended RD community included policymakers, industry, patients, and caregivers.
 - ✓ Codesign and facilitation of patient/caregiver empowerment labs.
 - ✓ Drafting and editing of co-produced national statements as well as consensus on participatory research, advanced research, and orphan drugs, biobanking and medicine, new-born screening, gen-ethics, and genomic editing, etc.
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- Dates (from - to)
 - Name and address of the employer
 - Type of business or sector
 - Occupation or position held
 - Main activities and responsibilities
- 2003 – 2011
 IRCCS Ca' Granda Foundation, Milan (Italy)
- Translational medicine, Healthcare, international research
- Bioethicist, Director of the “Clinical Bioethics and Healthcare Governance Centre”, Consultant for the Informed Consent Governance**
- ✓ **Creation, implementation & leading of:**
 - the Bioethics Centre,
 - the Evaluation and Permanent Institutional Board for Informed Consent,
 - the digital platform with differentiated access for the governance of all informed consents and for the co-production of new information paths.
 - ✓ Co-design, implementation, and coordination of participatory/research in action projects (for instance Biobanking together; Informed consent as a participatory process and good practice indicator; *Il consenso in corsia*. Towards a participatory governance of information processes...).
 - ✓ Participatory labs (more than 100) involving decisions-makers, clinicians, researchers, administrative staff, patients, citizens, and their representatives.
 - ✓ Drafting and editing publications and how-to-guide institutional documents.

- Dates (from - to) 2003 – 2006
- Name and address of the employer Istituto di Sociologia Internazionale di Gorizia, Gorizia (Italy)
- Type of business or sector Sociology of Science; international research
- Occupation or position held **Researcher**
 - Main activities and responsibilities PROGROW - Policy options for responding obesity. TRUSTNET 2 - Governance, health, and the environment. The Caffaro case. Writing and Editing of Publications

- Dates (from - to) 2003-2005
- Name and address of the employer Società italiana di Pedagogia Medica, SIMPa
- Type of business or sector **Palliative Medicine, Training**
- Occupation or position held Trainer, national education committee member
 - Main activities and responsibilities Design, development, and coordination of training courses in the field of palliative care and bioethics. Teaching bioethics to health care personnel.

- Dates (from - to) 1998-2003
- Name and address of the employer Universidad Complutense, Faculty of Medicine
- Type of business or sector **Research & Education, Public health, Bioethics**
- Occupation or position held **Bioethics Researcher, Honorary Professor**
 - Main activities and responsibilities Clinical Bioethics research, Scientific support for the master's degree in bioethics, teaching bioethics and exercises.

EDUCATION AND TRAINING

- Dates (from - to) 2018-2020
- Name and type of organisation providing education and training Università degli Studi di Milano-Bicocca, Italy
- Principal subjects/occupational skills covered **Executive Master's in Management of Research Infrastructures - EMMRI**
- Title of qualification awarded **Full Master** – Master Field Project: “Raising Awareness of Research Infrastructures: The Milano - Bicocca Case”.

- Dates (from - to) 1998 – 2001
- Name and type of organisation providing education and training Universidad Complutense de Madrid, Faculty of Philosophy, Spain
- Principal subjects/occupational skills covered **Ethics and Practical Philosophy, Qualitative and Quantitative Research Methods**
- Title of qualification awarded **Diploma of advanced doctoral studies**

- Dates (from - to) 1998 - 2001
- Name and type of organisation Università degli Studi di Siena, Faculty of Medicine, Italy
- Principal subjects/occupational skills covered **Biomedical Research, Clinical ethics/bioethics, deliberative methods, participatory approaches** (democratization of both science and medicine)
- Title of qualification awarded **PhD in Deontology and Clinical Ethics with distinction** - PhD Thesis “Ethical deliberation and clinical practice”

- Dates (from - to)
- Name and type of organisation providing education and training
- Principal subjects/occupational skills covered
- Title of qualification awarded

1997 - 1999

Universidad Complutense de Madrid, Faculty of Medicine, Spain

“Magister in Bioetica Clinica” – master’s in Clinical Bioethics

Full Master

- Dates (from - to)

1989 - 1995

- Name and type of organisation providing education and training

Università Cattolica del Sacro Cuore, Faculty of Philosophy, Italy

- Principal subjects/occupational skills covered

Theoretical philosophy, ethics, logic, philosophy of science

- Title of qualification awarded

Degree in Theoretical Philosophy cum laude

PERSONAL SKILLS AND COMPETENCES

MOTHER TONGUE

OTHER LANGUAGES

ITALIAN

ENGLISH, SPANISH, FRENCH

SCIENTIFIC SKILLS AND COMPETENCES

Living and working with other people, in multicultural environments, in positions where communication is important and situations where teamwork is essential (for example culture and sports), etc.

Bioethicist by training but a practical philosopher by imprinting, very fond of participatory approaches & deliberative methods, understanding and implementing bioethics as a process of both democratization of science and citizen engagement. As a bioethicist, I have been dedicated to biomedical and scientific research in a horizon of participatory, ELSI & RRI action constantly engaging with the diverse players.

I started in 2003, in the IRCCS Fondazione Ca’ Granda (Italy's leading hospital for translational medicine), and in parallel, I participated in the setup of both the Italian National Node, included its ELSI national service, and the ELSI Common Services of BBMRI-ERIC. Meanwhile at the university level, I’ve been improving an interactive, capability approach (and the related ELSI & RRI services) to empower and engage researchers within a post-normal science and RRI horizon.

These pluralist, multidisciplinary experiences and environments contribute to create and enhance:

- ✓ Well-established mediation skills and senior expertise in facilitating working groups in multidisciplinary and plural contexts (i.e., national ELSI working groups inclusive of patients, citizens, and Research Ethics Committees together with researchers, experts, biobankers; Socratic dialogues and deliberative sessions with diverse actors, etc.),
- ✓ Senior Expertise and ease in promoting teamwork with members belonging to different disciplines and/or nationalities, for the work carried out not only at RI European and National level, but also in the field of Palliative Medicine and with Scientific Societies, Federations of General Practitioners and Paediatricians, Patient/Citizen Associations, Charities and Professional Associations,
- ✓ Senior expertise and competence in both participatory approaches and research governance for scientific ethics as well as healthcare/research policy,
- ✓ Modelling and implementing empowerment settings with a dedicated focus on vulnerability scenarios,

- ✓ Co-producing with Patient/Citizen Organizations empowerment training programs and ELSI services, with a special attention to RD and Cancer communities, and for young generation, collaborating with School Umbrella Organizations,
- ✓ Senior Ability to create, plan, coordinate public events, public information pathways to promote inclusion and engagement (i.e., European Researchers' Night, Play-Decide events, Open doors in the biobanks, European Biotech Week),
- ✓ Senior Expertise in developing inclusive informational and communication tools: from the interactive site for the informed consent governance to the campaigns for cord blood donation, to the ELSI-COVID 19 section in BBMRI.it website,
- ✓ Consolidated expertise in developing both guidelines and consensus in multidisciplinary areas,
- ✓ Teaching skills acquired both academically and, in the field, with particular attention to interactive didactics for adults,
- ✓ Evidence of high-level research in action.

Soft skills

- Good listener
- Team player
- Strategic thinker
- Creative & innovative
- Facilitating networking and inclusive/pluralist/participatory environments
- Overcoming obstacles by turning them into resources; resilient
- Able to work under (time) pressure without losing your smile

ACHIEVEMENTS AND SERVICES

Coordination and administration of people, projects and budgets; at work, in voluntary work (for example culture and sports) and at home, etc.

Senior research in national and international projects such as Trust-net-2, PORGROW; national ELSI trainer and consultant for SIPEM (Italian Society for Medical Education); scientific director of the Research Centre of Bioethics and Healthcare Governance, at Ca' Granda Foundation.

At the forefront with Eurordis, UNIAMO, the Rare Disease Italian Federation, and many patient and citizen Organizations, I have been coordinating national projects dealing with ELSI issues of advanced research, with special attention to biomolecular fields, genetic/cellular therapies (included no-validated therapies due to the Italian Stamina case) & rare diseases, translational medicine, and next generation biobanking.

In 2013-2014 thanks to "Determinazione Rara" funded by Social Policy Minister, with patients and Agenzia Italiana del Farmaco - AIFA, Telethon Network of Genetics Biobanks, BBMRI_IT, Centro Nazionale Malattie Rare - CNMRI - ISS, I pioneered an innovative systemic empowerment focusing on collaborative science and inclusion as the key-factor.

Senior community and project manager promoting 2.0 tools and co-production knowledge processes, such as multidisciplinary Play Decide-debate events during the Global/European Biotech Weeks as well as the European Researchers' night, or Socratic dialogues around high complexity issues.

In the course of my work, I have set up from scratch and led:

- the Research Centre of Bioethics and Healthcare Governance in the IRCCS Fondazione Ca' Granda (Italy's leading hospital for translational medicine),
- the ELSI helpdesk and the ELSI services for the BBMRI Italian National Node,
- InfraUNIMIB, a tailored university service to improve RI ESFRI culture and partnership within the different scientific communities (Bicocca University, Milan),

- RRI service at university level (Bicocca University, Milan).

Coordinator in drafting and editing National and European ELSI statements, recommendations, how-to-guide documents.

As member of many Research Ethics Committees/IRBs/Advisory Boards as well as President of Milano-Bicocca University Ethics Committee I have a privileged observatory on frontiers issues of Advanced research and Scientific Ethics.

RELEVANT PUBLICATIONS

- ✓ How to guide: next-generation biobanking, biobanking with next-generation (co-authors B.Ellul) 2024 [10.5281/zenodo.11400119](https://doi.org/10.5281/zenodo.11400119)
- ✓ Common conditions of use elements. Atomic concepts for consistent and effective information governance” (coauthors: Sanchez Gonzalez, M.d.C., Kamerling, P., Iermito, M. et al.) *Sci Data* 11, 465 (2024). <https://doi.org/10.1038/s41597-024-03279-z>
- ✓ “ELSI challenges with children in translational Medicine” (coauthor: Ellul B) *Contemporary Issues in Clinical Bioethics - Medical, Ethical and Legal Perspectives* [Working Title]. IntechOpen; 2024. Available from: <http://dx.doi.org/10.5772/intechopen.1002550>
- ✓ “Paediatric biobanking for public health: the ethical legal and societal landscape” (coauthors: Ellul B, Mayhofer M.T, Lavitrano M, Caboux E, Kozlakidus Z) *Front. Public Health*, 27 September 2022 Sec. Children and Health. <https://doi.org/10.3389/fpubh.2022.917615>
- ✓ “The CORBEL matrix on informed consent in clinical studies: a multidisciplinary approach of Research Infrastructures Building Enduring Life-science Services” (Coauthors: Colombo C, et All) *BMC Med Ethics* 22, 95 (2021). <https://doi.org/10.1186/s12910-021-00639-x>
- ✓ Recommendations for collection, transport and storage of COVID-19 biological samples. Version of April 15, 2020. ISS COVID-19 Translational Research Working Group 2020
- ✓ BBMRI-ERIC ELSI Webinar COVID-19 Q&As v1 (Coauthors: Jahns R, et All). May 2020. <https://doi.org/10.5281/zenodo.3839273>
- ✓ “Ricerca e sperimentazione cliniche” in *Monitorare. Rapporto sulla condizione della Persona con Malattia Rara in Italia (2018 to 2020)*. Uniamo F.I.M.R. Onlus. http://www.uniamo.org/wpcontent/uploads/2019/07/monitorare_2019_web_v3.pdf
- ✓ “Data in question: A survey of European biobank professionals on ethical, legal and societal challenges of biobank research” (Coauthors: Goisaufer M, et All) *Plos*: September 18. <https://doi.org/10.1371/journal.pone.0221496>
- ✓ “Enhancing Reuse of Data and Biological Material in Medical Research: From FAIR to FAIR-Health”. (Coauthors: Holub P, Kohlmayer F, Prasser F, Mayrhofer MT, Schlünder I, Martin GM, Koumakis L, Wutte A, Kozera Ł, Strapagiel D, Anton G, Zanetti G, Sezerman OU, Mendy M, Valík D, Lavitrano M, Dagher G, Zatloukal K, van Ommen GB, Litton JE) *Biopreserv Biobank*. 2018 Apr;16(2):97-105. doi:10.1089/bio.2017.0110. Epub 2018 Jan 23
- ✓ “Biobanking: towards increased access of biomaterials in cystic fibrosis.” (co-authors: Beekman JM, Wang M, Tuggle K, Gulmans V, Amaral M, De Boeck K.) Report on the pre-conference meeting to the 13th ECFS Basic Science Conference, Pisa, 30 March-2 April 2016. *Journal of Cystic Fibrosis* 16 (2017) 616–621
- ✓ “Aspetti Etici” in *Programma di screening neonatali per le malattie metaboliche ereditarie (a cura di G. Andria) n.s. Prospettive in Pediatria*. Vol 45. 178 (Aprile-Giugno 2015):143-159
- ✓ “Promoting engagement in chronic illness: a collaborative research pathways”. (Coautori: S. Gilardi, C. Guglielmetti, P. Monti *Psicologia della salute*.1, 2014
- ✓ “Partnering with the health care team: Quality of service and sense of belonging in adults with beta thalassemia major”. *Psicologia della salute*. 2012 (1):87-109
- ✓ “Il consenso in corsia: un laboratorio di governance e buona pratica clinica”, *Complessità in medicina (a cura di F. Bonino)*. Edizioni Plus: Pisa 2012; cap.IV: 75-107
- ✓ Definizione, finalità, organizzazione, requisiti strutturali e tecnologici, consenso informato, privacy e modalità di accesso per le biobanche oncologiche (AA.VV) 2013 AIOM – SIAPEC [publicazioni/docUfficiale/DocumentazioneScientifica/Biobanche_06-06-13.pdf](http://www.aiom.it/publicazioni/docUfficiale/DocumentazioneScientifica/Biobanche_06-06-13.pdf)
- ✓ Vademecum per una buona pratica del biobanking – Vademecum for good practice in biobanking. UNIAMO F.I.M.R. onlus 2014

- ✓ Vademecum per una buona pratica del consenso informato nella ricerca – Vademecum for good practice of informed consent to research. UNIAMO F.I.M.R. onlus 2014
- ✓ “Xenotransplantation through history”. Scientific, ethical, social and legal aspects of xenotransplantation. (Casabona, Azofra, Cozzi Eds). Xenome 2012; chp.1: 19-32
- ✓ “Tu che mi interroghi, tu che mi ridefinisci: partecipazione, bioetica, età evolutiva” in Scegliere per la propria salute prima dei 18 anni. Franco Angeli 2010
- ✓ “From Actors to Authors: patients involved in the Informed Consent Governance within one of the major Italian Translational Research Hospitals”. Supplement of Journal of Ambulatory Care Management. 33, 3 (2010): 231–240. DOI: 10.1097/JAC.0b013e3181e5630d
- ✓ “An analysis of decision making in cord blood donation through a participatory approach” n.s. Transfusion. 42, 3(2010): 299-305
- ✓ Per una buona pratica del consenso informato. Linea Guida istituzionale. (a cura di). Fondazione Ca’ Granda IRCCS Ospedale Maggiore Policlinico: 2008 Milano
- ✓ Policy options for responding obesity. Porgrow. Italian. (Coauthor: G, Tarlao) Quaderni dell’Istituto Internazionale di Gorizia: Gorizia 2006
- ✓ La deliberazione etica e la pratica clinica – Ethical deliberation and clinical practice. Edizioni Medico Scientifiche: Torino 2003

AWARDS

- ✓ International Tiziano Terzani Award for Medical Humanities, Scuola di Umanizzazione in medicina, Alba.
- ✓ National Award De Sandre for Clinical Bioethics activities, Verona University.

To view the matrices included the ELSI matric for Research Ethics Committees to review both the institution of a biobank and biobank-based-research projects, ELSI tools, and recommendations that I edited, go directly to the following links:

<https://www.bbmri.it/en/nodo-nazionale/elsi-covid/strumenti-informativi/>
<https://www.bbmri.it/en/strumenti-e-prodotti/>

According to law 679/2016 of the Regulation of the European Parliament of 27th April 2016, and to the D.Lgs. n. 196/2003 and ss.mm., I hereby express my consent to process and use my data provided in this CV for the purpose of carrying out the selection procedure.

Milan, 23.10.2024

Signature

