

CURRICULUM VITAE

Personal Details

Family name: Di Iorio
Given names: Concetta Tania
Year of birth: 1967
Place of birth: Rome, ITALY
Nationality: Italian, Australian
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Languages: Italian, English

Education

2003 Master of Public Health (MPH), Monash University, Melbourne, Australia
Stream: General; *Final Grade:* Distinction
1993 Laurea in Law, University of Bologna (LL.M)
Final grade: 105/110 (High Distinction)
Subject: Commercial Law
Thesis: "Cooperation and Specialization Agreements among enterprises according to European Union Antitrust Law"
1987 *High School Diploma in Sciences*

Professional Qualifications

1998 Barrister, Italy, Abruzzo Court of Appeal, Italy
Grade: Distinction
1995 Solicitor, Council of Layers' Association, Pescara Tribunal, Italy

2002-today

Legal consultant

- 2015-2021 Legal-financial supervision and coordination (Senior Project manager) of various EU research projects (e.g. EPN2020-RI, EUROPLANET, Fly-Radar) sponsored by European Commission (Horizon 2020) for IRSPS, University G. D'Annunzio, Pescara, Italy.
- 2015-2021 Independent Ethics evaluator for the European Commission in 7th Framework Programme and Horizon 2020 projects (139 expert evaluator contracts)
- 2014-2020 Legal-financial coordination and management (Senior Project manager) of the BioVacSafe project, sponsored by IMI JU, for the University of Surrey, Guildford, UK.
- 2015-2017 Member of the Advisory Expert Group (O.E.C.D) for the development of “Council Recommendation on Privacy-Protective Uses of Personal Health data”.
- 2015-2017 Leader of task “Privacy Performance and Ethics Assessment” in the BRIDGE-Health project, sponsored by the European Commission (CHAFEA), subcontractor of The University Tor Vergata, Roma, Italy.
- 2014 Member of the OECD Advisory Panel on Health Information Infrastructure
- 2013-2014 Official Delegate Member of the EUBIROD Network (<http://www.hirs-research.eu/eubirod/members.html>) and Member of the EUBIROD Network Steering Committee.
- 2008-2012 Leader of the task “Privacy impact assessment” and associated project partner of the EUBIROD Project (www.eubirod.eu)
- 2008 Feasibility study for the Kuwait Diabetes Register, Dasman Centre for Research and Treatment of Diabetes, Kuwait City, Kuwait
- 2005-2008 Leader of the WP: “Privacy Impact Assessment” of the BIRO Project (www.biro-project.eu), subcontractor for the University of Perugia, Italy.
- 2004-2005 Independent Evaluator for the European Commission, Research Directorate General, Directorate F – Health, Strategy and Policy, 6th Framework Programme (e.g.: FP6 Science and Society, LIFESCIHEALTH)
- 2003 International Legal Consultant, Honorary Research Associate, Member of TIDE (Task force for the International Development in Europe), Monash Institute of Health Services Research, Monash University, Melbourne
- 2002-2003 Research Associate, Monash Institute of Health Services Research (General Staff, HEW Step 6), expert in EU public health research and policy projects

Computer Expertise

Information Search, Report Writing, Presentations:

- OS: MS Windows, Linux Fedora
- Office Automation: MSOffice/OpenOffice/LibreOffice (Word processing, Spreadsheet)

Professional Associations

2000-2007	Italian List of Lawyers (Barristers). Deliberation of Lawyers Association Council at the District of Pescara's Tribunal (Italy) in date 19 th April 2000.
1995-1999	Italian List of Lawyers at lower Courts (Solicitors). Deliberation of the Lawyers Association Council at the District of Pescara's Tribunal (Italy) in date 23 rd June 1995.

Professional Profile

Expertise:

C.T. Di Iorio is a lawyer with a specific and unique competence in public health, in particular on the analysis of legal and Ethical issues in the conduction of research studies and in the development of national/international health information infrastructure. In her activity, she has gained significant skills in the preparation and submission of successful EU project proposals, as well as in the direct participation to international collaborative activities.

Specific areas of expertise include:

- Privacy Impact and Performance Assessment of Health Information Systems, Privacy & Confidentiality of health data under EU law and Ethics
- EU Projects Coordination and management
- Public Health, Health Law, Ethics, Human Rights, Health Economics, Health Services Organization, Social Epidemiology
- EU Antitrust Legislation, Commercial Law, European Union Law, European Union Commercial Law and International Law
- Social implications of the treatment and analysis of health information - constraints and effects of privacy legislation on health research - ethics in health research - ethics in international data exchange within and outside EU - relationship between health policy and health economics

Biography:

- C.T.Di Iorio graduated in law at the University of Bologna in Italy.
- From 1993 to 2000 she has practised as a lawyer in the city of Pescara, Italy.
- In 2000 she founded Serectrix snc, a consulting firm specialized in knowledge transfer for evidence-based policy-making in public health and coordination and management of EU funded projects, based in Pescara, Italy.
- Between 2000 and 2003 she studied and graduated at the Master of Public Health, Monash University, Australia.
- Between 2004 and 2012 she collaborated at the preparation and implementation of the EU BIRO and EUBIROD project proposals, funded by the EU Commission (DG-SANCO), delivering new methods for privacy impact and performance assessment in the distributed analysis of diabetes information.
- In 2013 she contributed to the creation of the HIRS, joining the EUBIROD Network.
- In 2014 she entered the OECD Advisory Board on Health Information Infrastructure.
- From 2014 to 2020 she collaborated with the University of Surrey, Guildford (UK) for the Legal-financial coordination and management (as Senior Project Manager) of the BioVacSafe project, sponsored by IMI JU.
- From 2015 to 2017 she collaborated with the University of Tor Vergata, Roma (Italy) to carry out the “Privacy Performance and Ethics Assessment” of the BRIDGE-Health project, sponsored by the European Commission (CHAFEA).
- From 2015 to 2017 she participated in the Advisory Expert Group (O.E.C.D.) for the production of the “Council Recommendation on Privacy-Protective Uses of Personal Health data”, enacted by the OECD Council of Ministries in January 2017.
- From 2015 to 2021 she collaborates with IRSPS, Pescara, Italy for the Legal-financial supervision, coordination and management of the various EU projects (e.g.: EPN2020-RI, EUROPLANET, Fly-Radar) sponsored by European Commission (Horizon 2020).
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Career Highlights:

- International collaborations in the field of public health, privacy and data protection (Monash University, European Commission, OECD).
- Conceived and developed new methods of privacy impact and performance assessment.
- Collaborated with field experts for the provision of recommendations for the revision of European legislation on privacy and data protection.
- Collaborating with field experts to the OECD “Council Recommendation on Privacy-Protective Uses of Personal Health data”, enacted in January 2017.

EXPERT NOMINATED BY THE OECD

1. Advisory Expert Group (O.E.C.D.) for the development of “Council Recommendation on Privacy-Protective Uses of Personal Health data”, OECD Conference Centre, Paris, 30 November 2015
2. Advisory Panel of Experts on Health Information Infrastructure, OECD Conference Centre, Paris, 20 May 2015
3. Advisory Panel of Experts on Health Information Infrastructure, OECD Conference Centre, Paris, 21 May 2014
4. Joint Consultation of the OECD Health Care Quality Indicators Expert Group and the Working Party on Information Security and Privacy, OECD Headquarters, Paris, 11 May 2012

EU PROJECT ASSOCIATED PARTNER

- BRIDGE-Health Meeting, Nicosia, Cyprus, 20-24 September 2017
- BRIDGE-Health Meeting, Rome, Italy, 25-26 November 2015
- BRIDGE-Health Meeting, Guildford, UK, 24-25 August 2015
- EUBIROD Final Meeting, Larnaca, Cyprus, 24th-25th February 2012
- Third BIRO Academy Residential Course, Brussels, Belgium, 26th-27th August 2011
- Second BIRO Academy Residential Course, Brussels, Belgium, 22-25th January 2011
- Special BIRO Academy Meeting, Rome, 4-5th June 2010
- First BIRO Academy Residential Course, Kuwait City, Kuwait, 2-4th May 2009
- EUBIROD Kick-off Meeting, Brussels, Belgium, 29-30th November 2008
- BIRO 6th Technical Meeting, Brussels, Belgium, 29th November 2008
- EUBIROD Pre Kickoff Meeting, Rome, 21st April 2008
- BIRO 5th Technical Meeting, Rome, Italy, 20-21st April 2008
- EUBIROD Consortium Agreement Meeting, Rome, Italy, 4th December 2007
- BIRO 4th Technical Meeting, Rome, Italy, 3rd December 2007
- BIRO 2nd Investigators' Meeting Larnaca, Cyprus, 23-26th May 2007
- BIRO 1st Technical Meeting Dundee, Scotland, 6-7th March 2006
- BIRO Kick-Off Meeting, Perugia, Italy, 5th December 2005
- BIRO Consortium Agreement Meeting, Assisi, Italy, 1st May 2005
- Multilevel Diabetes Initiative Workshop, Monash University Prato, Italy, 28th February 2002

FULL PAPERS

1. Di Iorio CT, Carinci F, Oderkirk J, Smith D, Siano M, de Marco DA, de Lusignan S, Hamalainen P, Benedetti MM, *Assessing data protection and governance in health information systems: a novel methodology of Privacy and Ethics Impact and Performance Assessment (PEIPA)*. J. Med Ethics 2020;0:1–8. doi:10.1136/medethics-2019-105948. Available at: <https://jme.bmj.com/content/early/2020/03/27/medethics-2019-105948>
2. Chan T, Di Iorio CT, Lo Russo D, Kuziemy C, Teng Liaw S, de Lusignan S, *The UK National Data Guardian for Health and Care's Review of Data Security, Consent and Opt-Outs: leadership in balancing public health with rights to privacy?* Journal of Innovation in Health Informatics, 2016;23(3):627–632, DOI: <http://dx.doi.org/10.14236/jhi.v23i3.909>. Available at: <https://hijournal.bcs.org/index.php/jhi/article/view/909/948>
3. Liyanage H, Teng Liaw S, Di Iorio CT, Kuziemy C, Schreiber R, Terry AL, de Lusignan S, *Building a privacy & ethics framework for real world computerised medical record system data: A Delphi study*; Primary Health Care Informatics Working Group contribution to the Year Book of Medical Informatics; 2016: IMIA Yearbook 2016; pages:138-145; ISSN: 0943-4747, DOI: <http://dx.doi.org/10.15265/IY-2016-035>. Available at: <http://imia.schattauer.de/contents/archive/issue/2422/issue/special/manuscript/26819/show.html>
4. De Lusignan S, Liyanage H, Di Iorio CT, Chan T, Liaw S-T. Using routinely collected health data for surveillance, quality improvement and research: Framework and key questions to assess ethics, privacy and data access. J Innov Health Inform. 2015;22(4):426–432. Available at: <http://dx.doi.org/10.14236/jhi.v22i4.845>
5. Cunningham, Scott; Carinci, Fabrizio; Brillante, Massimo; Leese, Graham; McAlpine, Ritchie; Azzopardi, Joseph; Beck, Peter; Bratina, Natasa; Boucquet, Valery; Doggen, Kris; Jarosz-Chobot, Przemyslaw; Jecht, Michael; Lindblad, Ulf; Moulton, Tony; Metelko, Zeljko; Nagy, Attila; Olympios, George; Pruna, Simion; Skeie, Svein; Storms, Fred; Di Iorio, Concetta; Massi Benedetti, Massimo; *Defining a European diabetes data dictionary for clinical audit and healthcare delivery: core standards of the EUBIROD project* (Manuscript ID: ME15-01-0016.R1), Methods of Information in Medicine, Methods Inf Med. 2016;55(2):166-76. doi: 10.3414/ME15-01-0016. Epub 2015 Dec 15
6. Di Iorio CT, Carinci F, Oderkirk J, *Health Research and Systems' Governance are at risk: should the right to data protection override health?*, Journal of Medical Ethics, 2013 Dec 5. IF: 1.419
7. Di Iorio CT, Carinci F, Brillante M, Azzopardi J, Beck P, Bratina N, Cunningham SG, De Beaufort C, Debacker N, Jarosz-Chobot P, Jecht M, Lindblad U, Moulton T, Metelko Ž, Nagy A, Olympios G, Pruna S, Røder M, Skeie S, Storms F, and Massi Benedetti M, *Cross-border flow of health information: is “privacy by design” enough? Privacy performance assessment in EUBIROD*, Eur J Public Health. 2013 Apr;23(2):247-53, Epub 2012 May 4. IF: 2.313

8. Carinci F, Di Iorio CT, Ricciardi W, Klazinga N and Verschuuren M, *Revision of the European Data Protection Directive: opportunity or threat for public health monitoring?* Eur J Public Health. 2011 Dec;21(6):684-7. Epub 2011 Jul 23. IF: 2.313, available at: <http://eurpub.oxfordjournals.org/content/21/6/684.long>
9. Di Iorio CT, Carinci F, Azzopardi J, Baglioni V, Beck P, Cunningham S, Evripidou A, Leese G, Loevaas KF, Olympios G, Orsini Federici M, Pruna S, Palladino P, Skeie S, Taverner P, Traynor V and Massi Benedetti M, *Privacy Impact Assessment in the design of transnational public health information systems: the BIRO project*, Journal of Medical Ethics, 2009 35: 753-761, IF: 2.160.
10. Carinci F, Roti L, Francesconi P, Gini R, Tediosi F, Di Iorio CT, Bartolacci S, Buratti E. *The impact of different rehabilitation strategies after major events in the elderly: the case of stroke and hip fracture in the Tuscany region*, BMC Health Services Research 2007, 7:95, IF: 1.630. Available at: <http://www.biomedcentral.com/1472-6963/7/95>
11. Di Iorio CT, *International cooperation and privacy law: Implications of Australian, Italian and European Union data protection systems for collaborative health research*, Bulletin of the Italian Scientific Community in Australasia, March 2003, p.17-26. Available at: http://www.adscienanberra.org/archivio_b_01to09/2003March.pdf

ABSTRACTS

1. Carinci F, Massi Benedetti M on behalf of the EUBIROD Consortium, *Pooled analysis of quality of care indicators from diabetes registers of 19 European countries: results of the EUBIROD project*, IDF World Diabetes Conference, Melbourne, Australia, 2-6 December 2013.
2. Carinci F, Massi Benedetti M on behalf of the EUBIROD Consortium, *A validated privacy enhanced statistical platform for global diabetes monitoring: design and use of the BIRO system across nineteen European countries*, IDF World Diabetes Conference, Melbourne, Australia, 2-6 December 2013.
3. Di Iorio CT, Carinci F, *Cross-border flow of health information for public health: privacy by design or revision of the EU Data Protection Directive? The case of diabetes registers in Europe*, 3rd European Public Health Conference, Amsterdam, The Netherlands, 10-13 November 2010, Eur J Public Health 2010 (20) Suppl.1:101-102. Available at: http://eurpub.oxfordjournals.org/content/20/suppl_1.toc
4. Carinci F, Baglioni V, Di Iorio CT, Rossi L, Azzopardi J, Beck P, Cunningham S, Skeie S, Olympios G, Pruna S, Massi Benedetti M, *A novel framework for the routine production of EU indicators: the BIRO system*, Health services research into European policy and practice, European Conference on Health Services Research, Den Haag, Netherlands, 8-9 Aprile 2010. Available at: http://www.eubirod.eu/documents/poster/BIRO_poster_HSR_the_hague_10.pdf
5. F.Carinci on behalf of the EUBIROD Consortium, *A Novel International Framework for Privacy-Enhanced Data Processing, Exchange, and Pooled Analysis of Disease Registers: The European BIRO/EUBIROD Projects*, Academy Health Research Meeting 2010, Boston, Massachusetts, USA, June 2010. Available at: <http://www.academyhealth.org/files/2010/tuesday/carincif.pdf>

6. Di Iorio CT, Carinci F, Azzopardi J, Beck P, Cunningham S, Skeie S, Olympios G, Pruna S, Massi Benedetti M, the BIRO Consortium. *Defining the best architecture for secure data exchange of diabetes information in Europe: privacy impact assessment in the BIRO project*, Abstract Book of the IDF World Diabetes Congress, P-1609, pag. 545, Montreal, Canada, 18-22 October 2009.
7. Carinci F, Rossi L, Massi Benedetti M, BIRO Consortium, *An open source statistical engine for the automatic production of standardized diabetes indicators within and across regions: results of the BIRO project*, IDF World Diabetes Congress, P-1604, pag.543, Montreal, Canada, 18-22 October 2009
8. Carinci F, Massi Benedetti M, EUBIROD Consortium, *Monitoring diabetes outcomes across Europe, and beyond: the EU DG SANCO funded EUBIROD project*, IDF World Diabetes Congress, D-0721, pag.244, Montreal, Canada, 18-22 October 2009
9. Carinci F, Azzopardi J, Baglioni V, Beck P, Cunningham S, Skeie S, Olympios G, Pruna S, Traynor V, Massi Benedetti M, BIRO Consortium, *A novel standard to support information delivery for the fulfilment of IDF policy in Europe: results of the EU DG SANCO funded BIRO project*, IDF World Diabetes Congress, O-0402, pag.139, Montreal, Canada, 18-22 October 2009
10. The BIRO Collaborators, *Building a Shared European Diabetes Information System: results from the first year of activity of the EU Project "Best Information through Regional Outcomes" (B.I.R.O.)*, 19th Congress of the International Diabetes Federation, Cape Town, South Africa, 3-7 December 2006

BOOKS (CHAPTERS)

1. Di Iorio CT, Carinci F, Massi Benedetti M, *The Diabetes Challenge: from Human and Social Rights to the Empowerment of People with Diabetes*, In Ele Ferrannini, Paul Zimmet, Ralph DeFronzo and George Alberti editors, International Textbook of Diabetes Mellitus (ITDM), 4th edition, Chapter on Life with Diabetes Problems: Human and Social Rights. Published Online: 6 MAR 2015. DOI: 10.1002/9781118387658.ch76
2. Carinci F, Di Iorio CT, Massi Benedetti M, *Standardized information exchange in diabetes: integrated registries for governance, research and clinical practice*, in Bruttomesso D, Grassi G, editors, Technological Advancements in the Treatment of Type 1 Diabetes, Front Diabetes. Basel, Karger, 2014, vol 24, pp 1–14.
3. Di Iorio CT, Carinci F. *Privacy and Health Care Information Systems: Where Is the Balance?* In Carlisle G, Whitehouse D, Duquenoy P, editors, eHealth: Legal, Ethical and Governance Challenges, Springer-Verlag, UK, 2013.
4. The BIRO Consortium, *Final Report of the BIRO Project*, BIRO Monograph, Perugia 2009.
Available at:
http://www.biro-project.eu/documents/downloads/D14_4_BIRO_Monograph.pdf

TECHNICAL REPORTS

1. Di Iorio CT, Privacy and Ethics Impact and Performance Assessment (PEIPA) Final Report, BRIDGE-Health Project, October 2017.
2. Di Iorio CT et al. Privacy Impact Assessment Report: “Privacy Performance Assessment” of EUBIROD Registers, EUBIROD Consortium, March 2012 Update. Available at: http://www.eubirod.eu/documents/downloads/D5.2_final_update_2012.pdf.
3. Di Iorio CT et al. Privacy Impact Assessment Report, EUBIROD Consortium, September 2010. Available at: http://www.eubirod.eu/documents/downloads/D5_2_Privacy_Impact_Assessment_281111.pdf
4. Di Iorio CT, The BIRO Privacy Impact Assessment, BIRO Technical Report, available at: http://www.biro-project.eu/documents/downloads/D5_4_PIA_step4_Final_Report.pdf
5. Di Iorio CT, The BIRO Privacy Impact Assessment Step 3, BIRO Technical Report, available at: http://www.biro-project.eu/documents/downloads/D5_3_PIA_Privacy_Analysis.pdf
6. Di Iorio CT. The BIRO Privacy Impact Assessment Step 2, BIRO Technical Report, available at: http://http://www.biro-project.eu/documents/downloads/D5_2_PIA_Data_Flow_Analysis.pdf
7. Di Iorio CT. The BIRO Privacy Impact Assessment Preliminary Report, BIRO Technical Report, available at: http://www.biro-project.eu/documents/downloads/D5_1_Preliminary_PIA_Report.pdf

Selected Presentations

1. Di Iorio CT, Privacy and Ethics Impact and Performance Assessment of the BRIDGE-Health Project, BRIDGE-Health Project, Cyprus Meeting, 20-24 September 2017.
2. Di Iorio CT, Privacy Impact Assessment in the BIRO Project, BIRO Academy 2nd Residential Course, the EUBIROD Project, Brussels, Belgium, January 2011. Available at: http://www.eubirod.eu/academy/second_course/lectures/di_iorio.html
3. C.T.Di Iorio, F.Carinci, EUBIROD Consortium. Health services research and privacy protection in Europe: where is the balance? Bridging the gap to optimise the impact of the EU Data Protection Directive. EUPHA Conference 2010, Amsterdam, Netherlands, 12th November 2010. Available at: http://www.healthservicesresearch.eu/hsr_database/health_services_research_and_privacy_protection_in_europe_where_is_the_balance_bridging_the_gap_to/134
4. F. Carinci, V. Baglioni, C.T. Di Iorio, L. Rossi, J. Azzopardi, P. Beck, S. Cunningham, S. Skeie, G. Olympios, S. Pruna, M. Massi Benedetti. A novel framework for the routine production of EU indicators: the BIRO system. European Working Conference on Health Services Research, The Hague, Netherlands, April 2010. Available at: https://www.surfgroepen.nl/sites/hsr-europe/SiteCollectionDocuments/Posters/87_Fabrizio.Carinci.pdf

5. Di Iorio CT, Disease Registers and Privacy Protection: the case of Diabetes in the EUBIROD Project, BIRO Academy Special Meeting, the EUBIROD Project, Rome, Italy, June 2010. Available at:
http://www.eubirod.eu/academy/special_meeting/presentations/diiorio_policy_PIA_040610.pdf
6. Di Iorio CT, Privacy Impact Assessment in the BIRO Project, BIRO Academy 1st Residential Course, the EUBIROD Project, Kuwait City, Kuwait, 2nd May 2009. Available at:
http://www.eubirod.eu/academy/first_course/lectures/PrivacyImpact_diiorio.htm



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