

# I dati della ricerca e la *data protection*

PRESENTAZIONE DELLA JOAL SPECIAL ISSUE  
ON «OPEN SCIENCE AND DATA PROTECTION»

*Ludovica Paseri, PhD.  
GenOA Week 2023,  
Università di Genova,  
24 ottobre 2023*



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# Di cosa parleremo?

1. Introduzione;
2. La JOAL special issue su «*Open Science and Data Protection*»;
3. L'approccio adottato: un'analisi a più livelli;
4. Conclusioni.

# 1. Introduzione

L'origine del progetto:



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Alma Mater Studiorum - Università di Bologna  
in cotutela con University of Luxembourg - Université du Luxembourg

DOTTORATO DI RICERCA IN  
LAW, SCIENCE AND TECHNOLOGY

Ciclo 34

Settore Concorsuale: 12/H3 - FILOSOFIA DEL DIRITTO  
Settore Scientifico Disciplinare: IUS/20 - FILOSOFIA DEL DIRITTO

THE EUROPEAN LEGAL APPROACH TO OPEN SCIENCE AND RESEARCH  
DATA

Presentata da: Ludovica Paseri



La relazione tra

Il trattamento  
dei dati  
personali per  
finalità di  
ricerca  
scientifica

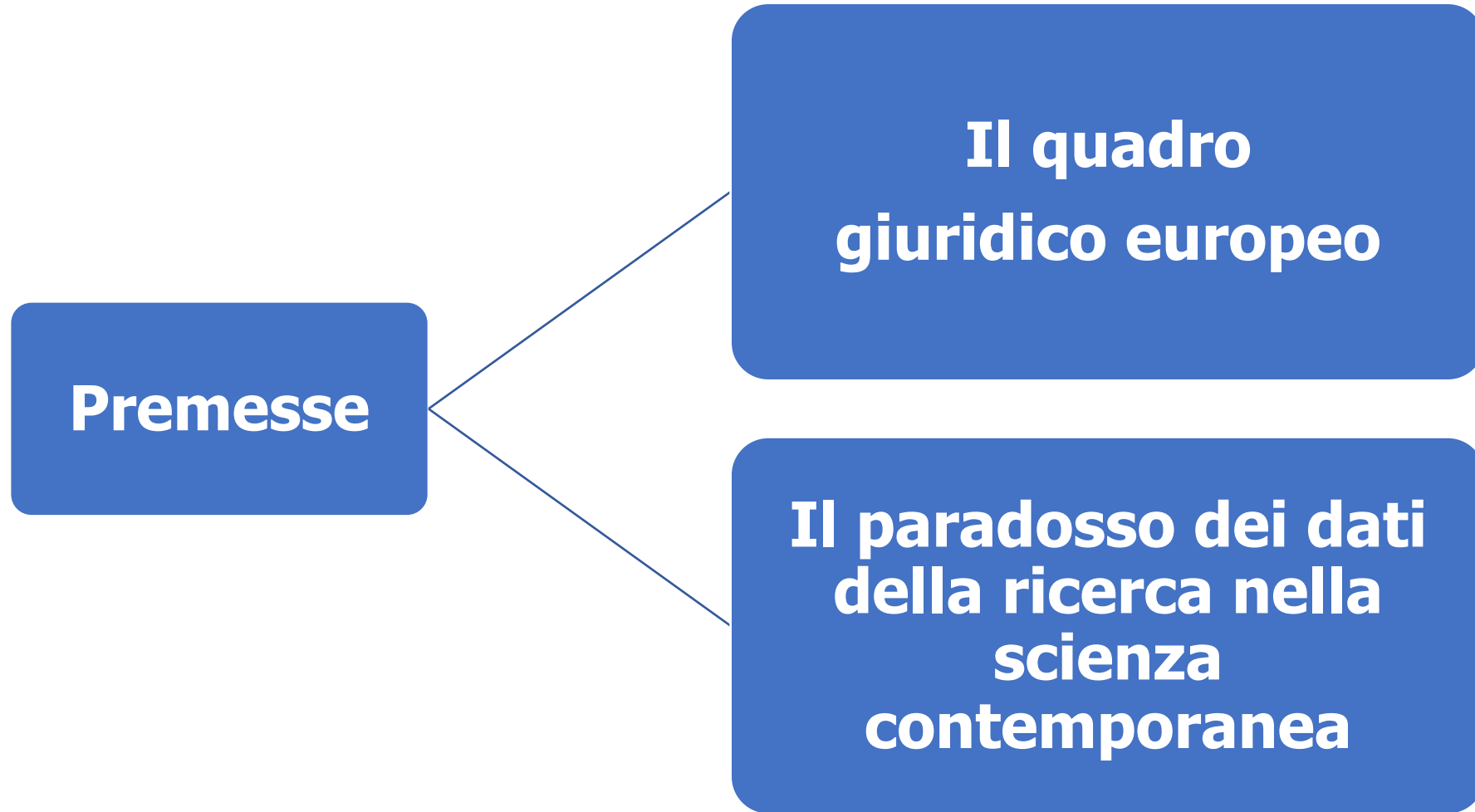
La scienza  
aperta e  
l'apertura dei  
dati della  
ricerca

<https://amsdottorato.unibo.it/10393/>

# 1. Introduzione



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# 1. Introduzione: prima premessa



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## I dati della ricerca nel quadro giuridico europeo



### GDPR

REGOLAMENTO (UE) 2016/679 DEL PARLAMENTO EUROPEO E DEL CONSIGLIO

del 27 aprile 2016

relativo alla protezione delle persone fisiche con riguardo al trattamento dei dati personali, nonché alla libera circolazione di tali dati e che abroga la direttiva 95/46/CE (regolamento generale sulla protezione dei dati)

**Table 1** The sources of data politics in EU law

Acronym	Year	Source	Subject
AIA	2021	COM/2021/206 final	Artificial intelligence
CEAP	2020	COM/2020/98 final	Circular economy
Chips Act	2022	COM/2022/46 final	Semiconductors
Cyber Act	2019	Regulation 2019/881	Cybersecurity
DAct	2022	COM/2022/68 final	Fair data access and use
DGA	2020	COM/2020/767 final	Data governance
DHC	2018	COM/2018/233 final	e-Health and care
DMA	2020	COM/2020/842 final	Digital markets
DSA	2020	COM/2020/825 final	Digital services
ECL	2021	Regulation (EU) 2021/1119	Climate
EHDS	2022	COM/2022/197 final	Health data space
EU DS	2020	COM/2020/66 final	Overall data strategy
GDPR	2016	Regulation 2016/679	Personal data
Green Deal	2019	COM/2019/640 final	Climate, environment
ODF	2019	Directive 2019/1024	Open data framework

Pagallo, U. The Politics of Data in EU Law: Will It Succeed?. *DISO* **1**, 20 (2022).  
<https://doi.org/10.1007/s44206-022-00021-3>

# 1. Introduzione: seconda premessa



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**Il paradosso dei dati  
della ricerca nella  
scienza contemporanea**

Open Science and Data Protection:  
Engaging Scientific and Legal Contexts

Ludovica Paseri\*  
*\*Post-Doc Research Fellow at the Law Department,  
Università degli Studi di Torino*

<https://ojs.law.cornell.edu/index.php/joal/article/view/137>

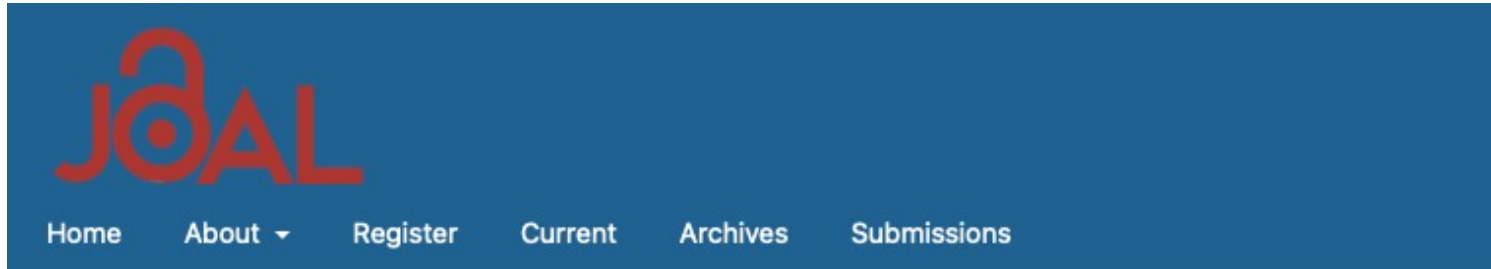
*Data-driven  
science*

Crisi riproducibilità  
o ripetibilità

## 2. La JOAL special issue su «*Open Science and Data Protection*»



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[Home](#) / [Archives](#) / Vol. 11 No. 1 (2023): Special Issue on "Open Science and Data Protection"

### Vol. 11 No. 1 (2023): Special Issue on "Open Science and Data Protection"

Editor: Ludovica Paseri

Special Issue on "Open Science and Data Protection" consists of 2 issues:

- [Vol. 11 No. 1 \(2023\)](#)
- [Vol. 11 No. 2 \(2023\)](#)

**Published:** 2023-09-21

### Prima parte

<https://ojs.law.cornell.edu/index.php/joal/issue/view/13>

### Seconda parte

<https://ojs.law.cornell.edu/index.php/joal/issue/view/14>

## 2. La JOAL special issue su «*Open Science and Data Protection*»



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### Prima parte

<https://ojs.law.cornell.edu/index.php/joal/issue/view/13>

JOAL Special issue on "Open Science and Data Protection"  
Part I Commentary:

On Not Taking Open for Granted

John Willinsky<sup>a</sup>  
<sup>a</sup>Stanford University

<https://ojs.law.cornell.edu/index.php/joal/article/view/135>

### Seconda parte

<https://ojs.law.cornell.edu/index.php/joal/issue/view/14>

JOAL Special issue on "Open Science and Data Protection"  
Part II Commentary:

The protection of personal data for the purpose of scientific  
research and the Open Science framework:  
Ongoing challenges and future opportunities.

Veronique Ciminà<sup>a</sup>  
<sup>a</sup>European Data Protection Supervisor (EDPS)\*

<https://ojs.law.cornell.edu/index.php/joal/article/view/145>

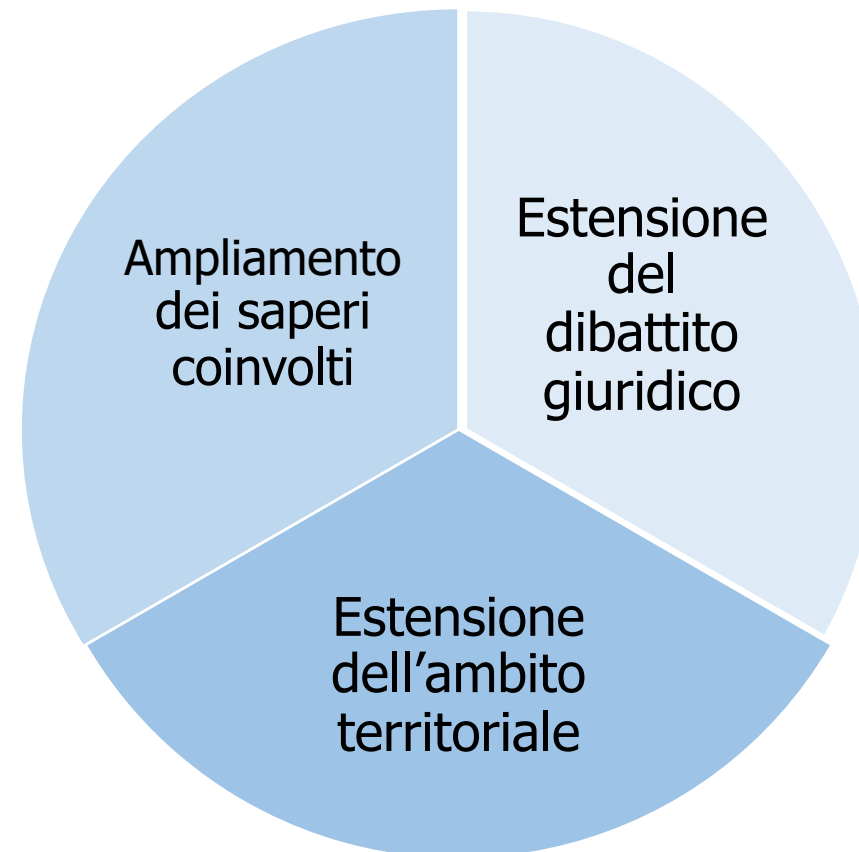


## 2. La JOAL special issue su «*Open Science and Data Protection*»



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Necessità alla base dell'analisi



# 3. L'approccio adottato

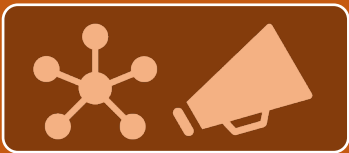


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## Le sfide tra apertura e protezione



**Contestuale ed epistemologica**



**Di coordinamento giuridico**



**Tecnica**



**Di governance**

# 3. L'approccio adottato



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## Sfida Contestuale ed epistemologica

Open? The only way forward for science

Elena Giglia\*

\*University of Turin, UNITO, Open Science Unit

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Openness in Scientific Research: A Historical and Philosophical Perspective

David Resnik\*

\*National Institute of Environmental Health Sciences (NIEHS)

<https://ojs.law.cornell.edu/index.php/joal/article/view/132>

Reconciling Open Science with Technological Sovereignty: Can the European Union do it?

Luc Soete\*, Jean-Claude Burgelman<sup>o</sup>

\*Emeritus Professor, UNU-MERIT, Maastricht University, The Netherlands and Dean, Brussels School of Governance, Free University of Brussels (VUB), Belgium

<sup>o</sup>Professor and academic coordinator Open Science, Free University of Brussels (VUB), Belgium and Editor-In-Chief, Frontiers Policy Lab

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# 3. L'approccio adottato



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## Sfida di coordinamento giuridico

Scientific research processing health data in the European Union: data protection regime vs. open data

Giorgia Bincoletto\*

*\*Post-Doc Research Fellow at the Faculty of Law, University of Trento*

<https://ojs.law.cornell.edu/index.php/joal/article/view/139>

(Un)informed consent in Psychological Research: An empirical study on consent in psychological research and the GDPR

Dara Hallinan<sup>a</sup>, Franziska Boehm<sup>a</sup>, Annika Külpmann<sup>b</sup>, Malte Elson<sup>bc</sup>

<sup>a</sup>*FIZ Karlsruhe - Leibniz Institute for Information Infrastructure,*

<sup>b</sup>*Faculty of Psychology, Ruhr University Bochum,*

<sup>c</sup>*Institute of Psychology, University of Bern*

<https://ojs.law.cornell.edu/index.php/joal/article/view/140>

Circulation of personal data and non-personal data within the European Research Area for research and health purposes

Valentina Colcelli<sup>a</sup>, Roberto Cippitani<sup>b</sup>

<sup>a</sup>*CNR-Ifac,*

<sup>b</sup>*CNR-Ifac, INDEPAC - Instituto Nacional de Estudios Superiores en Derecho Penal (Mexico)*

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# 3. L'approccio adottato



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## Sfida tecnica

### Enabling Open Science in Medicine Through Data Sharing: An Overview and Assessment of Common Approaches from the European Perspective

Hammam Abu Attieh<sup>1\*</sup>, Anna Haber<sup>1\*</sup>, Felix Nikolaus Wirth<sup>1\*</sup>, Benedikt Buchner<sup>2</sup>, Fabian Prasser<sup>1\*</sup>

<sup>1</sup>*Berlin Institute of Health at Charité – Universitätsmedizin Berlin, Health Data Science Center, Medical Informatics Group, Charitéplatz 1, 10117 Berlin, Germany*

<sup>2</sup>*University of Augsburg, Chair for Civil Law, Liability Law and Law of Digitization, Universitätsstraße 2, 86159 Augsburg, Germany*

<https://ojs.law.cornell.edu/index.php/joal/article/view/142>

### Synthetic data: A convergence between Innovation and GDPR

Shalini Kurapati<sup>a</sup>, Luca Gilli<sup>a</sup>

<sup>a</sup>*Clearbox AI*

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# 3. L'approccio adottato



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## Sfida di governance

Policy and legislation challenges for Open Science:  
Developments in Australia

Roxanne Missingham\*

*\* Chief Scholarly Information Officer, Australian National University, Australia*

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Private and Academic AI Collaboration:  
Opportunities and Challenges to Open Science in the US

Anat Lior\*

*\* Assistant professor at Drexel University's Thomas R. Kline School of Law, an AI Schmidt affiliated Scholar with the Jackson School at Yale and an affiliated fellow at the Yale Information Society (LL.M., J.S.D. Yale Law School).*

<https://ojs.law.cornell.edu/index.php/joal/article/view/144>

Citizen-gathered data to support public services  
under emergencies: promises and perils of openness

Anna Berti Suman<sup>a</sup>

*<sup>a</sup> The European Commission's Joint Research Centre, Ispra, Italy*

<https://ojs.law.cornell.edu/index.php/joal/article/view/141>

# 4. Conclusioni

Relazione tra apertura e protezione:  
una possibile convergenza

La tensione poggia su un'errata premessa

Non vi sono dati empirici a sostegno del conflitto

Una fuorviante rappresentazione

Incertezza



Limite



Opportunità

Open Science and Data Protection:  
Engaging Scientific and Legal Contexts

Ludovica Paseri\*

\**Post-Doc Research Fellow at the Law Department,  
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