I dati aperti cemento della scienza: risultati dell’indagine Bibliosan per la Scienza Aperta (BISA)

Istituto Superiore di Sanità, Roma. 15 maggio 2017

OPEN DATA: LE PREOCCUPAZIONI DEI RICERCATORI

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Dati aperti – Scienza aperta

Grazie!

Gruppo di lavoro Bibliosan per la Scienza Aperta (BISA):

………attività di sensibilizzazione della comunita`scientifica nazionale e internazionale sui principi della scienza aperta, volte a diffondere una cultura di condivisione dei dati a supporto della ricerca

………indagine Bibliosan per la scienza aperta

Dati aperti – Scienza aperta

☐ **TEMA CHE È NECESSARIO AFFRONTARE**
- Ricercatori che producono dati
- Ricercatori che utilizzano dati

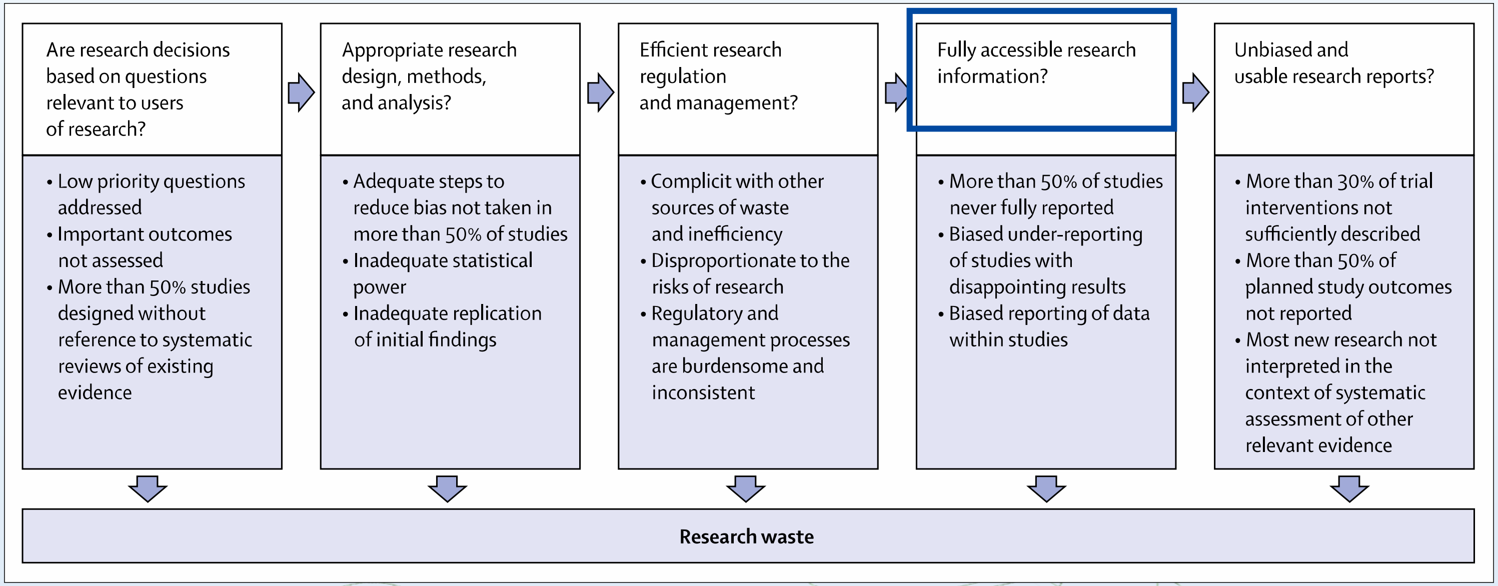
☐ **PREOCCUPAZIONE**
- Mancanza di informazione/formazione
- Necessità di supporto IT, legale, etico

☐ **OPPORTUNITÀ**
- Valorizzazione della ricerca biomedica
- Uso ottimale delle risorse
- Migliorare la qualità della ricerca

Dati aperti – Scienza aperta

Biomedical research: increasing value, reducing waste

**Malcolm R Macleod,*



Are research decisions based on questions relevant to users of research?

- Low priority questions addressed
- Important outcomes not assessed
- More than 50% studies designed without reference to systematic reviews of existing evidence

Appropriate research design, methods, and analysis?

- Adequate steps to reduce bias not taken in more than 50% of studies
- Inadequate statistical power
- Inadequate replication of initial findings

Efficient research regulation and management?

- Complicit with other sources of waste and inefficiency
- Disproportionate to the risks of research
- Regulatory and management processes are burdensome and inconsistent

Fully accessible research information?

- More than 50% of studies never fully reported
- Biased under-reporting of studies with disappointing results
- Biased reporting of data within studies

Unbiased and usable research reports?

- More than 30% of trial interventions not sufficiently described
- More than 50% of planned study outcomes not reported
- Most new research not interpreted in the context of systematic assessment of other relevant evidence

Research waste

Figure: **Avoidable waste or inefficiency in biomedical research**

procedure dati

www.thelancet.com

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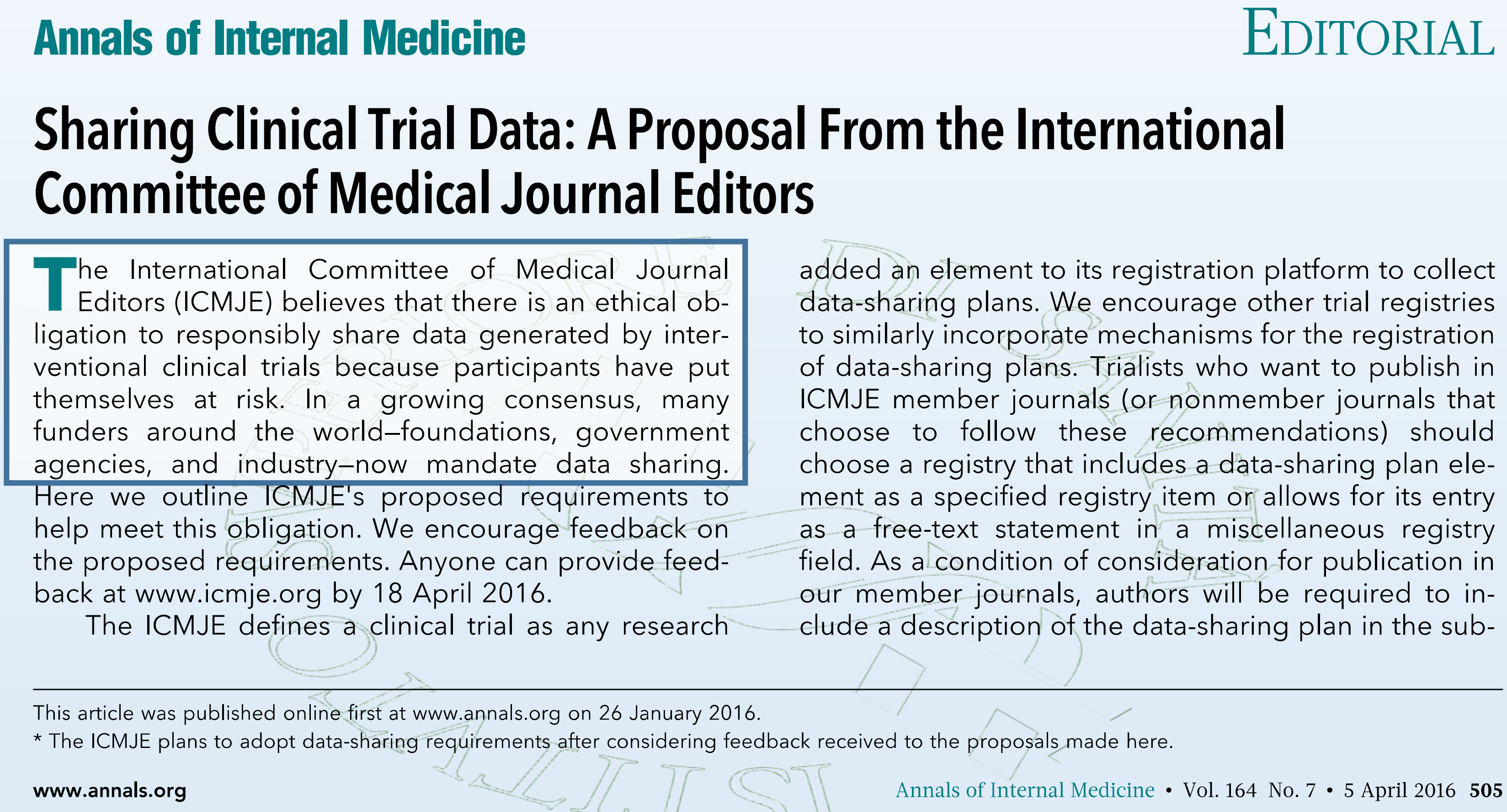
❑ TEMA CHE È NECESSARIO AFFRONTARE



Annals of Internal Medicine

EDITORIAL

Sharing Clinical Trial Data: A Proposal From the International Committee of Medical Journal Editors

The International Committee of Medical Journal Editors (ICMJE) believes that there is an ethical obligation to responsibly share data generated by interventional clinical trials because participants have put themselves at risk. In a growing consensus, many funders around the world—foundations, government agencies, and industry—now mandate data sharing. Here we outline ICMJE's proposed requirements to help meet this obligation. We encourage feedback on the proposed requirements. Anyone can provide feedback at www.icmje.org by 18 April 2016.

The ICMJE defines a clinical trial as any research added an element to its registration platform to collect data-sharing plans. We encourage other trial registries to similarly incorporate mechanisms for the registration of data-sharing plans. Trialists who want to publish in ICMJE member journals (or nonmember journals that choose to follow these recommendations) should choose a registry that includes a data-sharing plan element as a specified registry item or allows for its entry as a free-text statement in a miscellaneous registry field. As a condition of consideration for publication in our member journals, authors will be required to include a description of the data-sharing plan in the sub-

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This article was published online first at www.annals.org on 26 January 2016.

* The ICMJE plans to adopt data-sharing requirements after considering feedback received to the proposals made here.

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Dati aperti – Scienza aperta

DATA MANAGEMENT PLAN – GENERAL DEFINITION

Data Management Plans (DMPs) are a key element of good data management. A DMP describes the data management life cycle for the data to be collected, processed and/or generated by a **Horizon 2020 project**. As part of making research data findable, accessible, interoperable and re-usable (FAIR), a DMP should include information on:

- the handling of research data during and after the end of the project
- what data will be collected, processed and/or generated
- which methodology and standards will be applied
- whether data will be shared/made open access and
- how data will be curated and preserved (including after the end of the project).

A DMP is **required** for all projects participating in the extended ORD pilot, unless they opt out of the ORD pilot. However, projects that opt out are still **encouraged** to submit a DMP on a voluntary basis.

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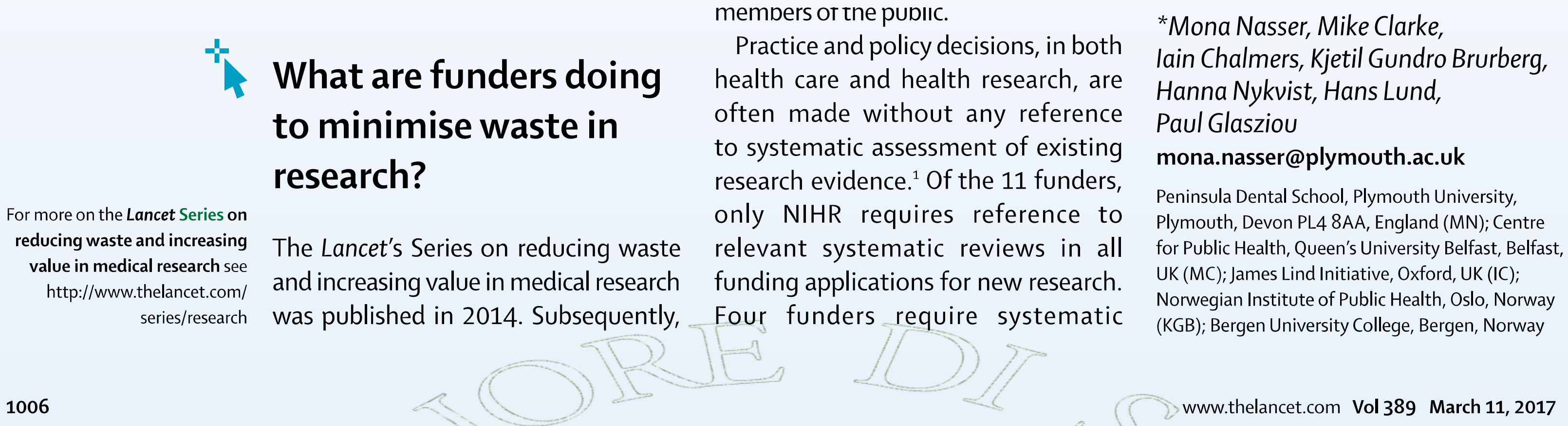
CONSENSO CRESCENTE MA………



For more on the *Lancet* Series on **reducing waste and increasing value in medical research** see http://www.thelancet.com/series/research

What are funders doing to minimise waste in research?

The *Lancet*'s Series on reducing waste and increasing value in medical research was published in 2014. Subsequently,

members of the public.

Practice and policy decisions, in both health care and health research, are often made without any reference to systematic assessment of existing research evidence.[1] Of the 11 funders, only NIHR requires reference to relevant systematic reviews in all funding applications for new research. Four funders require systematic

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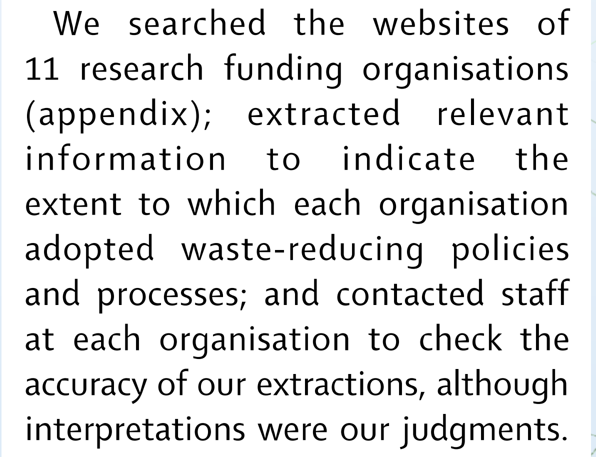
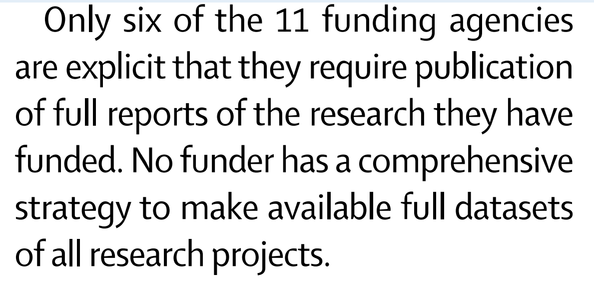


We searched the websites of 11 research funding organisations (appendix); extracted relevant information to indicate the extent to which each organisation adopted waste-reducing policies and processes; and contacted staff at each organisation to check the accuracy of our extractions, although interpretations were our judgments.



Only six of the 11 funding agencies are explicit that they require publication of full reports of the research they have funded. No funder has a comprehensive strategy to make available full datasets of all research projects.

Mancanza di strategia a livello di istituzioni di riferimento

Dati aperti – Scienza aperta

Elementi di Preoccupazione

- Mancanza di chiare linee guida
- Mancanza di un linguaggio comune (quali dati?)
- Necessità di supporto IT e di figure professionali dedicate
- Necessità di supporto legale, etico

➡ **La politica di gestione dei dati della ricerca deve essere elaborata e implementata a livello di istituzione, ma anche nazionale, europeo, internazionale**

➡ **Incentivo vs aggravio**

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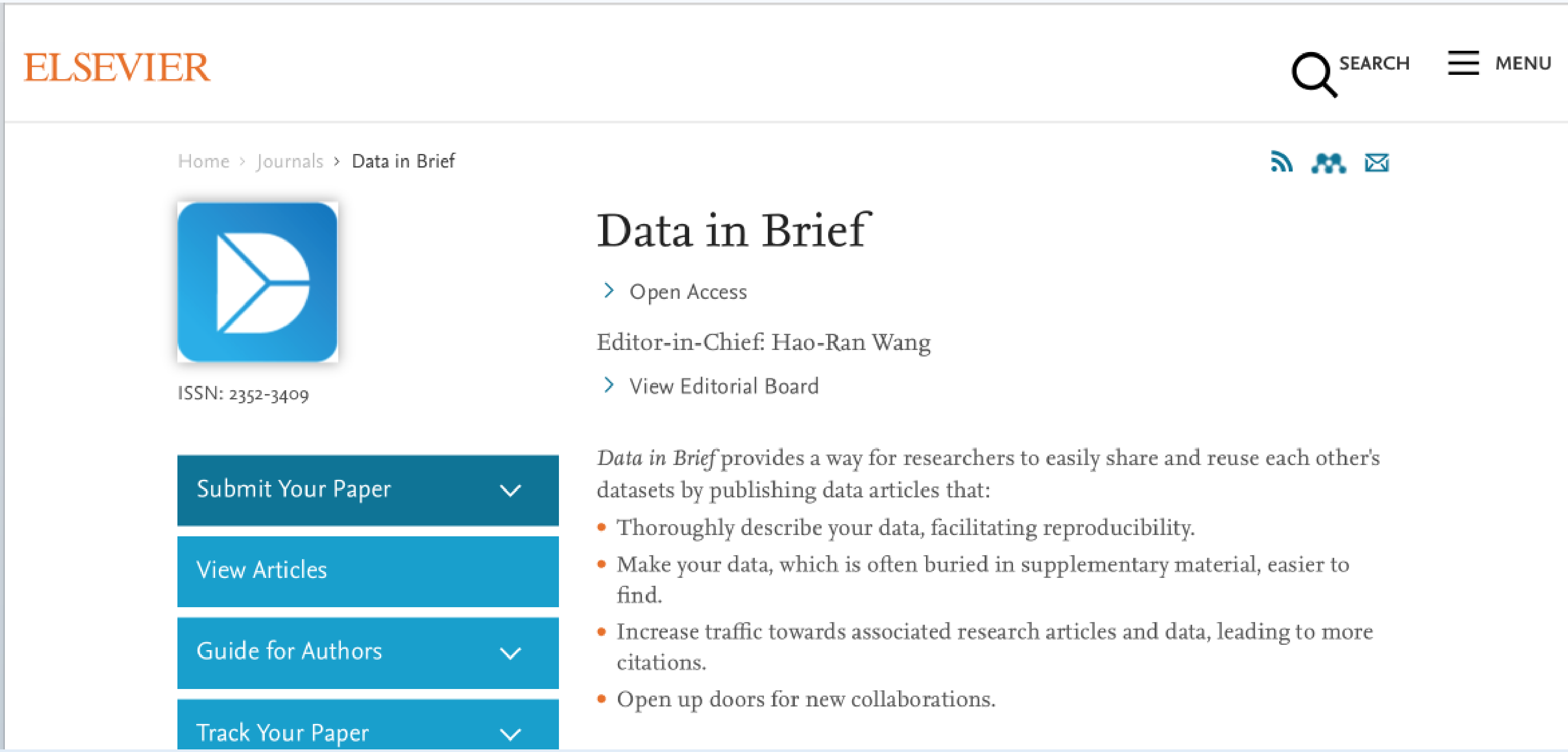
❑ OPPORTUNITÀ

- Valorizzazione della ricerca biomedica
- Migliorare e facilitare l’attività del ricercatore

Applicazione dei requisiti FAIR :
- **Maggior attenzione alla metodologia della ricerca e della gestione del dato**

Disponibilità di archivi aperti (data sharing):
- **evitare duplicazioni o errori nella fase di progettazione della ricerca**
- **Possibilità di ripetere l’analisi dei dati alla luce di nuove conoscenze**
- **migliorare l’attività di valutazione e revisione di progetti**

Politiche di incentivazione al “data sharing”:
- **sistema di riconoscimento *dell’authorship* dei dati della ricerca**
- **riconoscimento pubblicazione aperta dei dati come prodotto della ricerca**
- **quali archivi/piattaforme**



Data in Brief

› Open Access

Editor-in-Chief: Hao-Ran Wang

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ISSN: 2352-3409

Data in Brief provides a way for researchers to easily share and reuse each other's datasets by publishing data articles that:

- Thoroughly describe your data, facilitating reproducibility.
- Make your data, which is often buried in supplementary material, easier to find.
- Increase traffic towards associated research articles and data, leading to more citations.
- Open up doors for new collaborations.

You are welcome to convert your supplementary data (or a part of it) into a Data in Brief article. Data in Brief articles are descriptions of the data and associated metadata that are normally found in the supplementary material. They are actively reviewed, curated, formatted, indexed, given a DOI and freely available to all upon publication. Data in Brief should be uploaded with your revised manuscript directly to BBA - xxxxx. If your BBA – xxxxx research article is accepted, your Data in Brief article will automatically be transferred to our new, Open Access journal, Data in Brief, where it will be reviewed and published upon acceptance.

Dati aperti – Scienza aperta

❑ CONCLUSIONI

Importanza di:

- **avviare di percorsi conoscitivi e formativi sulle pratiche di gestione dei dati della ricerca in ambito biomedico**
- **promuovere iniziative (Gruppo di lavoro Bibliosan) con l’obiettivo di “allineare la comunita`di ricerca italiana agli standard internazionali di condivisione dei dati, tramite l’elaborazione di programmi e linee guida per l’adozione di pratiche comuni”**