

EUROPE BIOBANK WEEK

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Anne Cambon Thomsen: "Sample and data sharing for research: Why is it so vividly advocated and so poorly done? The route towards an enlightened future"



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BBMRI-ERIC

Biobanking and
BioMolecular resources
Research Infrastructure



Sample and data sharing for research

Anne Cambon-Thomsen et al.
Vienna, EBW, 13-16/9/2016



Sample and data sharing for research: Why is it so vividly advocated and so poorly done? The route towards an enlightened future

Dr. Anne Cambon-Thomsen, **CNRS** emeritus research director

UMR 1027 **Inserm** and **Univ Toulouse III** – Epidemiology & public health

Genotoul societal platform, Toulouse: « Genetics & society »

BBMRI-ERIC, Graz, Austria: Common Service ELSI



European Biobank Week, Vienna, 13-16/9/2016

Developing practices

Data sharing is becoming a major aspect of biomedical research

- science policy and practice
- community resources

Is this reality reflected in policies of encouragement of data sharing, or at least in clear instructions for researchers?

Gaps between principles and implementation.

What tools needed and what are available?

Why are such resource sharing important.... and poorly done?

Much biomedical/epidemiological research is based on using bioresources

- Their access to all relevant researchers is essential
- Promoting their **sharing** is crucial, but does not mean « just » putting files on the web!
- It requires work.... Poorly recognised
- There are today principles but few tools and ~ no incentive to that.

Questions on bioresources use and science integrity

In absence of guidance a number of questionable attitudes regarding bioresources use, sharing and reporting occur:

- absence of reporting of the use of a bioresource,
- non-optimal use of such resources while this is an ethical imperative with regard to the patients and research participants who provided their samples and data,
- non-traceability of material used with difficulty to reproduce results,
- lack of recognition of bioresource contribution to research,
- undue authorship as the only perceived way to foster academic recognition.

The problem of rewarding

- lack of recognition of the work implied by making resources available and usable by others,
- lack of standards for citation of resources used (until CpBRA, but still not very used)
- difficulty to get scientific/academic recognition other than through authorship
- legal uncertainty,
- ethical aspects where individual protection may conflict with collective benefit.



The Bioresource Research Impact Factor initiative

Anne Cambon-Thomsen, *leader*
Laurence Mabile, *project manager*

The BRIF initiative

www.gigasciencejournal.com/content/2/1/7

Work **in progress**, currently developing a **framework** for recognising the specific contribution of bioresources to Research (in scientific literature)

Final objective:

To create tools that will:

- promote a philosophy of sharing in the biomedical community
- facilitate the practice of sharing policies for data and samples

HOW?

By creating a set of adequate standardized tools:

- standards for citation / acknowledgement of bioresources in scientific articles
- BRIF indicator: a tool to establish frequency of BR use and evaluate their impact based on metrics with defined parameters
- Unique digital resource identifier (e.g; DOI, catalogue N°)
- Marker paper (providing a DOI)
- Connection between individual research ID (e.g. ORCID) and resource ID

Elements of the framework / tools

A set of adequate standardized tools:

- standards for citation / acknowledgement of bioresources in scientific articles (CoBRA)
- Marker paper (providing a DOI)
- Unique digital resource identifier (e.g; DOI, catalogue N^o)
- BRIF indicator: a tool to establish frequency of BR use and evaluate their impact based on metrics with defined parameters
- Connection between individual research ID (e.g. ORCID) and resource ID
- Policy analysis : which access policies do promote sharing.



CoBRA



Home Library Toolkits Courses & events

Bravo et al. BMC Medicine (2015) 13:33
DOI 10.1186/s12916-015-0266-y

Open Access

GUIDELINE

Developing a guideline to standardize the citation of bioresources in journal articles (CoBRA)

Elena Bravo^{1*}, Alessia Calzolari¹, Paola De Castro¹, Laurence Mabile², Federica Napolitani¹, Anna Maria Rossi¹ and Anne Cambon-Thomsen²

Abstract

Background: Many biomedical publications refer to data obtained from collections of biosamples. Sharing such bioresources (biological samples, data, and databases) is paramount for the present governance of research. Recognition of the effort involved in generating, maintaining, and sharing high quality bioresources is poorly organized, which does not encourage sharing. At publication level, the recognition of such resources is often neglected and/or highly heterogeneous. This is a true handicap for the traceability of bioresource use. The aim of this article is to propose, for the first time, a guideline for reporting bioresource use in research articles, named CoBRA: Citation of BioResources in Journal Articles.

Methods: As standards for citing bioresources are still lacking, the members of the journal editors subgroup of the Bioresource Research Impact Factor (BRIF) initiative developed a standardized and appropriate citation scheme for such resources by informing stakeholders about the subject and raising awareness among scientists and in science editors' networks, mapping this topic among other relevant initiatives, promoting actions addressed to stakeholders through launching surveys, and organizing focused workshops.

Results: The European Association of Science Editors has adopted BRIF's suggestion to incorporate statements on biobanks in the Methods section of their guidelines. The BRIF subgroup agreed upon a proposed citation scheme for each individual bioresource that is used to perform a study and that is mentioned in the Methods section of a paper. Each bioresource should be cited as an individual "reference [BIORESOURCE]" according to a delineated format. The EQUATOR (Enhancing the Quality and Transparency of health Research) network mentioned the proposed reporting guideline in

Home > Library > Reporting guideline > Developing a guideline to standardize

Search for reporting guidelines

Use your browser's Back button to return to your search results



Developing a guideline to standardize the citation of bioresources in journal articles (CoBRA)

Reporting guideline provided for? (i.e. exactly what the authors state in the paper)

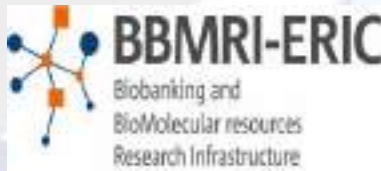
Citation of bioresources in journal articles

[CoBRA checklist \(PDF\)](#)

Full bibliographic reference

Bravo E, Calzolari A, De Castro P, Mabile L, Napolitani F, Rossi AM, Cambon-Thomsen A. Developing a guideline to standardize the citation of bioresources in journal articles. BMC Medicine. 2015;13:33. doi:10.1186/s12916-015-0266-y

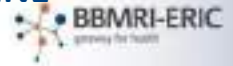
Promoted by BBMRI-ERIC :



Educational video:
By A. Calzolari, P Santoro & E. Bravo)
<https://zenodo.org/record/55785>

Go to E Bravo talk : in **E1**
Improved output quality of human biological material across European biobanks.
15/9/2016 – 8.30

BRIF SERVICES: THE CoBRA GUIDELINE



What is the guideline about?

The BRIF (*Bioresource Research Impact Factor*) initiative is building a framework that enables set up indicators for the use of bioresources* and rewarding mechanisms. Generated as part of the BRIF initiative, the CoBRA (*Citing Of Bioresources in Research Articles*) guideline provides guidance for citing bioresources in academic literature: it specifies where and how to cite bioresources at each section of a research article.

BBMRI-ERIC encourages the systematic use of the CoBRA guideline by the biobank community and supports the inclusion in MTA/DTAs.

* Bioresources are defined as collections of biological samples with associated data (medical/epidemiological, social), databases independent of physical samples or other collection of biomolecular and bioinformatics research tools.

KEY ELEMENTS:

To report in scientific journal articles:

▢ **Abstract** section: Indicate whether the work has used one or more bioresources, and specify the number of bioresources if relevant.

▢ **Introduction** section: Indicate that the work has used one or more bioresources. Specify the type.

▢ **Methods** section: Report each individual bioresource used to perform the study: By their name and other ID, if extant, and by a single bibliographic reference

▢ **References** section:

Cite each bioresource used as a reference as follows:

ID / Bioresource Name (acronym if available) / organization or network partnership, membership (optional) / Number of access(es), Date of last access; [BIORESOURCE]

Cite each bioresources referred to (but not used) as a reference as follows:

ID / Bioresource Name (acronym if available) / organization or network partnership, membership (optional)

Who is this guideline for?

The guideline is intended for any researcher or professional reporting on a research work using bioresources or referring to bioresources in a scientific journal article.

How can I engage?

Use the CoBRA checklist when writing a scientific article!

Download the CoBRA guideline at

<http://www.equator-network.org/reporting-guidelines/cobra/>

Who to contact?

BRIF: Laurence.Mabile@univ-tlse3.fr

CoBRA: Elena Bravo, elena.bravo@iss.it

What is BBMRI-ERIC?

BBMRI-ERIC is a distributed research infrastructure of *biobanks* and *biomolecular resources*. For its Member States, it provides expertise and services on a non-economic basis and facilitates access to collections of partner biobanks and biomolecular resources. BBMRI-ERIC is established for an unlimited period of time.

The power of marker papers

- The concept of “marker paper” has developed over years as the reference paper that **describes** a resource and must be cited when referring to it or to its use.
- It provides a DOI to the resource through its description.
- It is compatible with the CoBRA guideline.
- This allows follow up of its use.
- The credit of the paper is for the creators/managers of the bioresource.
- It clearly distinguish recognition for setting up/ maintaining a bioresource and results obtained using it.

See Poster 33

Collaboration with Ubiquity Press

Launch of an open access data journal dedicated to the publication of description of bioresources

Aim:

- Increase the visibility of bioresources by offering the possibility of an open access “marker paper”, according to an established template of



<http://openbioresources.metajnl.com>

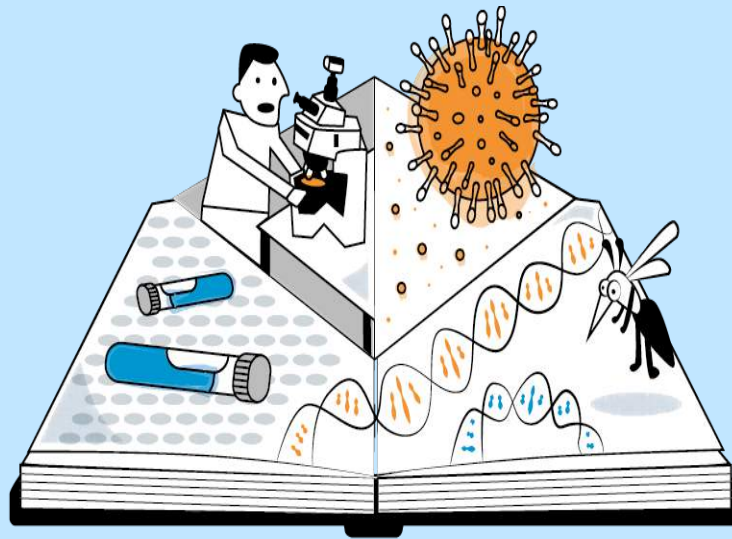
The *Open Journal of Bioresources (OJB)* features peer-reviewed short papers helping researchers to locate and cite bioresources with **high reuse potential**.

Making bioresources more openly discoverable has **enormous benefits** not only for the research community and the wider public, but for the producers of the bioresources as well.

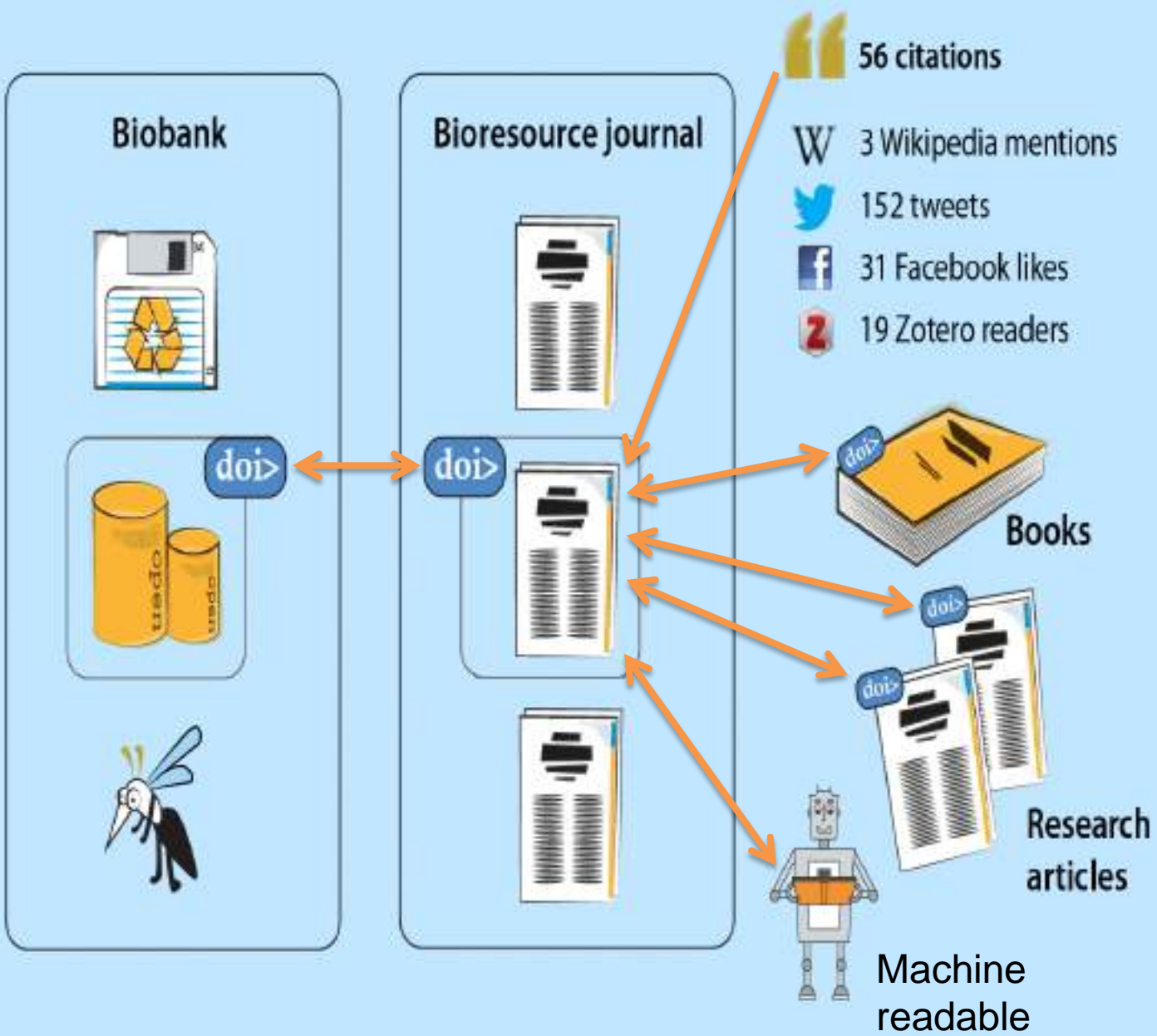
Both the resources and the OJB papers are **citable** and this will be tracked to

How it works

- OJB Bioresource papers are:
 - Short and concise
 - Peer reviewed
 - Open Access only (CC BY)
 - Fully citable
- Paper structure:
 - Abstract
 - Bioresource overview
 - Methods
 - Bioresource description
 - Reuse potential



OJB is searching for new reviewers! Register at :



Next steps

- Link with RDA : research data alliance

<https://rd-alliance.org/>



- Connection between individual research ID (e.g. ORCID) and resource ID.



www.orcid.org: Connecting Research and Researchers.

- Construction of the metrics (new subgroup to set up)
- Continue the sharing policies analyses.

CONCLUSION

Recognition and rewarding can only be achieved through coordinated tools and strategies

It necessarily involves challenging the world of metrics and science evaluation

The recognition of biobanking contribution to science touches on science policy and science evaluation at large.

Challenging, no?



Thank you!

Subscribe to the *BRIF Newsletter* at:
<http://listes.univ-tlse3.fr/wws/subscribe/brif.info>