RESEARCH INTEGRITY





26 February 2019

Presentation by Stefanie Van der Burght

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WHO AM I?

Stefanie Van der Burght

- Research Department (2012 ...)
 - ✓ Policy Advisor

Research Integrity and Ethics Advisor

- ✓ Trainer
- Secretary of the Commission for Research Integrity





WHAT IS (RESEARCH) INTEGRITY?



Take a moment (2') to think about this



WHAT IS INTEGRITY?

- Consists of : trait, attitude, competence
- Corresponds with norms, values, agreements, rules
- Requires: making decisions (and choices)

... Also under pressure

... Also when nobody is watching

- Is expressed in behavior: what do you do? Why? How?
- Is linked to ethics, moral judgement

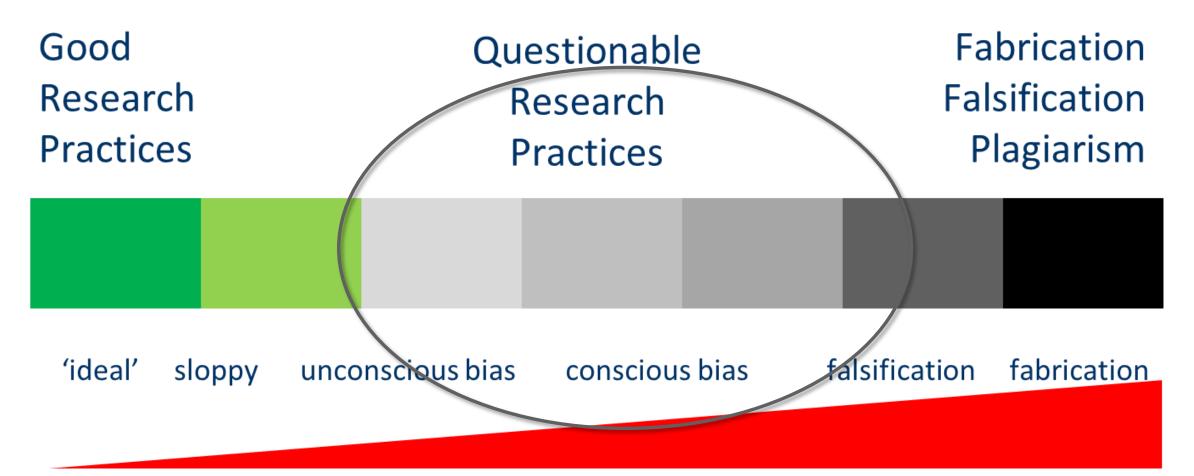


WHAT IS RESEARCH INTEGRITY?

- Subset of professional integrity
- Research deontology
- Norms, values, agreements, rules
- Quality ('good') research
- Research as proces
- Research as product/result



WHAT ARE WE TALKING ABOUT?





Source: D. Fanelli (adapted by VIB)

GOOD RESEARCH PRACTICES

Good Research Practices

Arts and Humanities

Responsible Conduct of Research

"Behaviours that follow the standards established by professionals and society for the proper conduct of research" Epigeum, Research Skills online, Research Integrity – unintentional, 'one-off' honest errors

BAD RESEARCH PRACTICES

Fabrication Falsification Plagiarism **Plagiarism Accusations**

Merkel's Education Minister Has Ph.D. Title Revoked

German Education Minister Annette Schavan has long been dogged by accusations that she had plagiarized parts of her Ph.D. thesis. Now, the University of Düsseldorf has revoked her degree. She may be forced to resign from Chancellor Angela Merkel's cabinet.

By Jörg Diehl ♥ and Oliver Trenkamp ♥ in Düsseldorf and Berlin

http://www.spiegel.de/international/germany/ education-minister-schavan-has-ph-drevoked-in-plagiarism-scandal-a-88107.html (2013)

"Behaviours that significantly compromise the accuracy of the research record or the proper professional conduct of research." Epigeum, Research Skills online, Research Integrity – Arts and Humanities

Fraude hoogleraar Stapel 'verbijsterend'

© 31-10-2011, 14:57 AANGEPAST OP 31-10-2011, 20:50 BINNENLAND

De commissie die onderzoek heeft gedaan naar het gesjoemel door hoogleraar Diederik Stapel in Tilburg, noemt de fraude verbijsterend.

http://nos.nl/artikel/308864-fraudehoogleraar-stapel-verbijsterend.html (2011)

QUESTIONNABLE RESEARCH PRACTICES



- 'cutting corners'
- Accumulation of sloppiness, errors
- Adjusting practices

"Behaviours that do not live up to the standards for responsible conduct but that are not seen as serious misconduct." Epigeum, Research Skills online, Research Integrity – Arts and Humanities

Questionable

Research

Practices

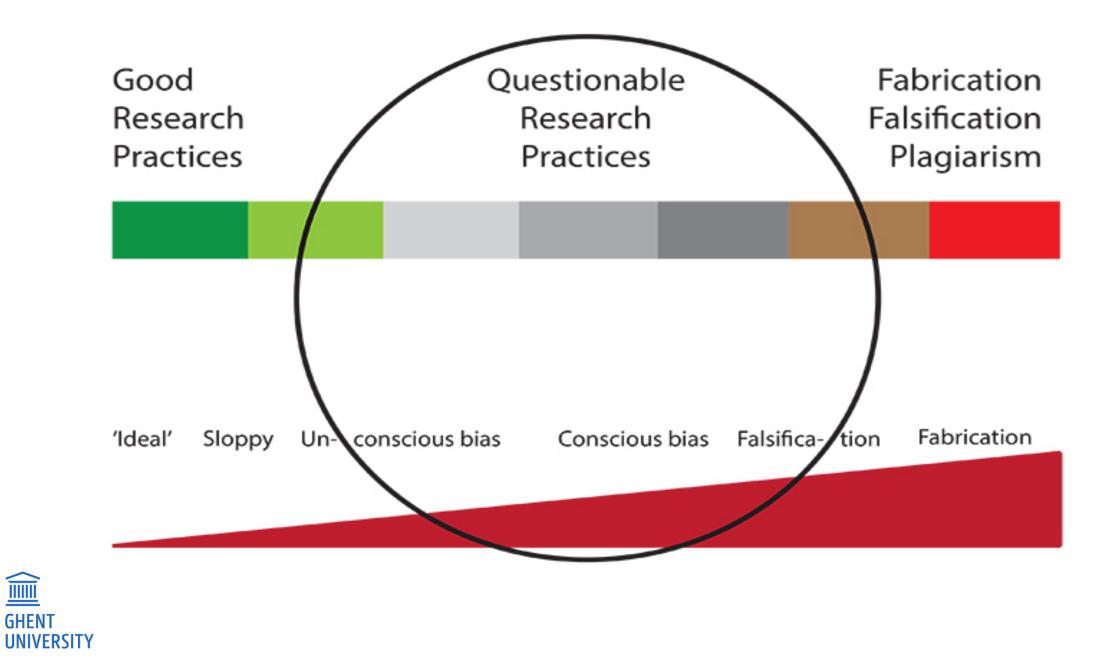




"There can be no first-class research without integrity."

Marja Makarow, in *A new code of conduct for researchers* (European Science Foundation, 2010)









THE SINGAPORE STATEMENT ON RI

PRINCIPLES -

Honesty in all aspects of research Accountability in the conduct of research **Professional courtesy and fairness** in working with others **Good stewardship** of research on behalf of others

1. Integrity: Researchers should take responsibility for the trustworthiness of their research.

2. Adherence to Regulations: Researchers should be aware of and adhere to regulations and policies related to research.

3. Research Methods: Researchers should employ appropriate research methods, base conclusions on critical analysis of the evidence and report findings and interpretations fully and objectively.

4. Research Records: Researchers should keep clear, accurate records of all research in ways that will allow verification and replication of their work by others.

5. Research Findings: Researchers should share data and findings openly and promptly, as soon as they have had an opportunity to establish priority and ownership claims.



6. Authorship: Researchers should take responsibility for trustworthiness Research institutions, as well as journals, professional reports and other representations of their research. Lists of data, or the use research, should have procedures for responding to authors should include all those and only those who meet applicable authorship criteria.

7. Publication Acknowledgement: Researchers should acknowledge in publications the names and roles of those who made significant contributions to the research, including writers, funders, sponsors, and others, but do not meet authorship criteria.

8. Peer Review: Researchers should provide fair, prompt and rigorous evaluations and respect confidentiality when reviewing others' work.

9. Conflict of Interest: Researchers should disclose financial and other conflicts of interest that could compromise the trustworthiness of their work in research proposals, publications and public communications as well as in all review activities.

10. Public Communication: Researchers should limit professional comments to their recognized expertise when engaged in public discussions about the application and importance of research findings and clearly distinguish professional comments from opinions based on personal views.

11. Reporting Irresponsible Research Practices:

Researchers should report to the appropriate authorities any suspected research misconduct, including fabrication, falsification or plagiarism, and other

irresponsible res 12. Responding to Irresponsible Research Practices:

their contributions to all publications, funding application improperly listin organizations and agencies that have commitments to

allegations of misconduct and other irresponsible research practices and for protecting those who report such behavior in good faith. When misconduct or other irresponsible research practice is confirmed, appropriate actions should be taken promptly, including correcting the research record.

13. Research Environments: Research institutions should create and sustain environments that encourage integrity through education, clear policies, and reasonable standards for advancement, while fostering work environments that support research integrity.

14. Societal Considerations: Researchers and research institutions should recognize that they have an ethical obligation to weigh societal benefits against risks inherent in their work.

THE EUROPEAN CODE OF CONDUCT FOR RI



The European Code of Conduct for Research Integrity REVISED EDITION





<u>4 VALUABLES</u>

 $\widehat{\blacksquare}$

GHENT UNIVERSITY

These principles are:

• **Reliability** in ensuring the quality of research, reflected in the design, the methodology, the analysis and the use of resources.

• **Honesty** in developing, undertaking, reviewing, reporting and communicating research in a transparent, fair, full and unbiased way.

• **Respect** for colleagues, research, participants, society, ecosystems, cultural heritage and the environment.

• Accountability for the research from idea to publication, for its management and organisation, for training, supervision and mentoring, and for its wider impacts.



The European Code of Conduct for Research Integrity REVISED EDITION



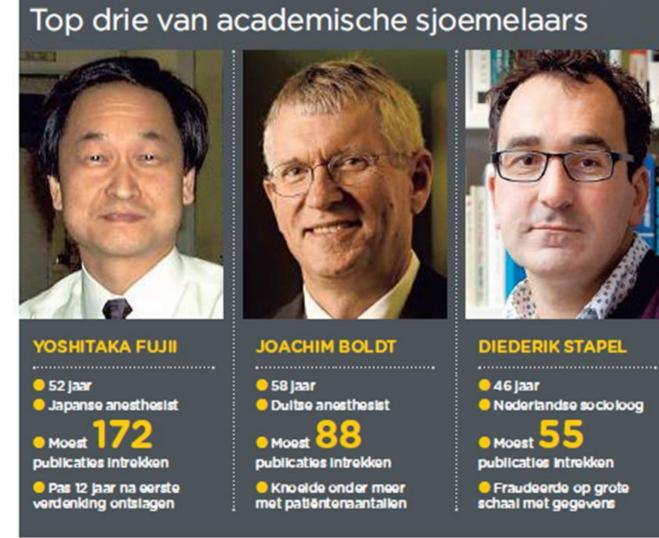
Fostering Responsible conduct of research FRCR 4x/py – 2/ps Check DS Newsletter for new dates!





FRCR – custom made workshop

BAD APPLES IN THE SCIENCE BUNCH



Source: De Morgen, 'Wetenschappelijke fraudeur krijgt levenslang' (Eline Delrue), 23/03/2013, pg.7



SOME NUMBERS

• FFP

(Fanelli, PloS ONE, 2009, p.1)

"A pooled weighted average of 1.97% (N = 7, 95%CI: 0.86–4.45) of scientists admitted to have fabricated, falsified or modified data or results at least once –a serious form of misconduct by any standard [...].

In surveys asking about the behaviour of colleagues, admission rates were 14.12% (N = 12, 95% CI: 9.91–19.72) for falsification [...]."

(Translated from EOS, April 2013, p.25)

"From 315 researchers who completed an extensive survey, 4 admit to having fabricated data one or several times in the last three years (1,3%)."



• QRP

(Fanelli, PloS ONE, 2009, p.1)

"[...] and up to 33.7% admitted other questionable research practices.

[In surveys asking about the behaviour of colleagues, admission rates were] up to 72% for other questionable research practices."

(Translated from EOS, April 2013, p.26-28) "[...] 69% admit that he/she added at least one coauthor without that person having a real input in the past three years" (gift authorship)

[...] [27% of the respondents admit to have left out data or observations based on a gut feeling]"



WHO ARE THEY, WHAT MOVES THEM? CAUSES

(Kornfeld, Academic Medicine, 2012)

Typology: 6 types

Misconduct = result of the interaction of psychological traits and the circumstances in which these individuals found themselves (~publication pressure)

(Tijdink et al., PlosOne, 2016)

Personality has an impact on research behavior (~Machiavellianism)



PERSONALITY





"Hey hon, I finally finished writing the first line of my book! It took me three months, but it's the BEST FIRST LINE EVER!! Wanna hear it? Hon?"

> INKYGIRL.COM: Daily Diversions For Writers Copyright©2008 Debbie Ridpath Ohi

"the perfectionist" for whom any failure was a catastrophe



"the desperate" whose fear of failure overcame a personal code of conduct





"the ethically challenged " who succumbed to temptation "the grandiose" who believed that his or her superior judgment did not require verification





"the sociopath" who was totally absent a conscience (and, fortunately, was rare) "the non professional support staff" who were unconstrained by the ethics of science, unaware of the scientific consequences of their actions, and/or tempted by financial rewards



ENVIRONMENT: PRESSURE







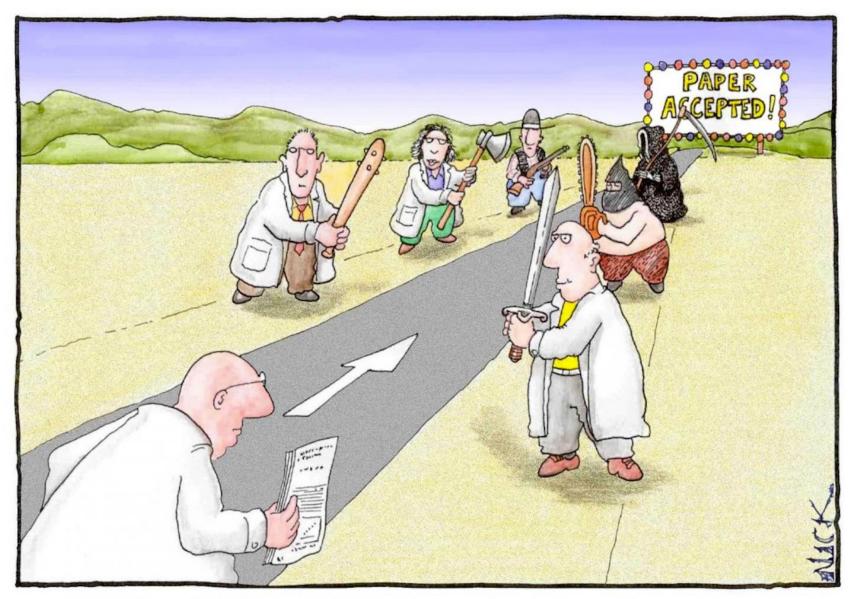


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ENVIRONMENT: LOW DETECTION - MYTH OF SELF-CORRECTION



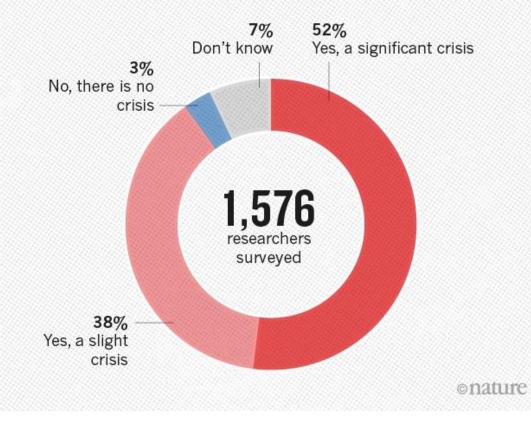






Most scientists regarded the new streamlined peer-review process as "quite an improvement."

IS THERE A REPRODUCIBILITY CRISIS?





PUBLICATIONS AND DATA



A TABLE OF TRAGEDIES

The factors that lead to bad decisions can be represented by the mnemonic TRAGEDIES. Here are some examples of each pitfall. Recognizing these and responding appropriately can save a career and strengthen science.

Temptation

"Getting my name on this article would look really good on my CV."

Rationalization

"It's only a few data points, and those runs were flawed anyway."

Ambition

"The better the story we can tell, the better a journal we can go for."

Group and authority pressure

"The PI's instructions don't exactly match the protocol approved by the ethics review board, but she is the senior researcher."

Entitlement

"I've worked so hard on this, and I know this works, and I need to get this publication."

Deception

"I'm sure it would have turned out this way (if I had done it)."

Incrementalism

"It's only a single data point I'm excluding, and just this once."

Gunsalus & Robinson, *Nine pitfalls of research misconduct*, Nature, 16/05/2018

Embarrassment

"I don't want to look foolish for not knowing how to do this."

Stupid systems

"It counts more if we divide this manuscript into three submissions instead of just one."





A WAY TO RESPOND: THE COMMITTEE FOR RI





<u>cwi@ugent.be</u> 09 264 95 59







LET'S PLAY A GAME!



DILEMMA GAME (ERASMUS U ROTTERDAM)



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DILEMMA FUN

- Read the dilemma
- Think about the decisive parameters
- Choose an option I will tell you when to press
- Check the poll to discover the answers of your group members
- Group discussion
- Ask questions



ISSUE #1 – AUTHORSHIP



FREE LUNCH?

I am starting my PhD project and as a first task I am asked to rewrite a paper by a former PhD colleague who has meanwhile left academia. I notice the paper needs only small changes and the reviewers are very mild and friendly, so the paper may get accepted in the next round. My professor suggests putting me as last author, to support my academic career, despite my limited contribution to the actual research process. He will be the first author. The former PhD has agreed that others can use his work, but no specific agreements were made.



WHAT WOULD BE YOUR OPTION?

- A. I agree to the offer and get listed as last author.
- B. I suggest that I should be mentioned in a footnote, but not listed as author.
- C. I contact the former PhD and ask him whether he wants the publication in his name.
- D. I decline the revising job; I do not want to be involved.



WHAT DOES THE CODE SAY?

<u>EU-code</u>:

• All authors agree on the **sequence of authorship**, acknowledging that authorship itself is based on a **significant contribution** to the **design** of the research, relevant **data collection**, or the **analysis or interpretation** of the results.

• Authors acknowledge important work and intellectual contributions of others, including collaborators, assistants, and funders, who have influenced the reported research in appropriate form, and cite related work correctly

• All authors are **fully responsible for the content** of a publication, unless otherwise specified.



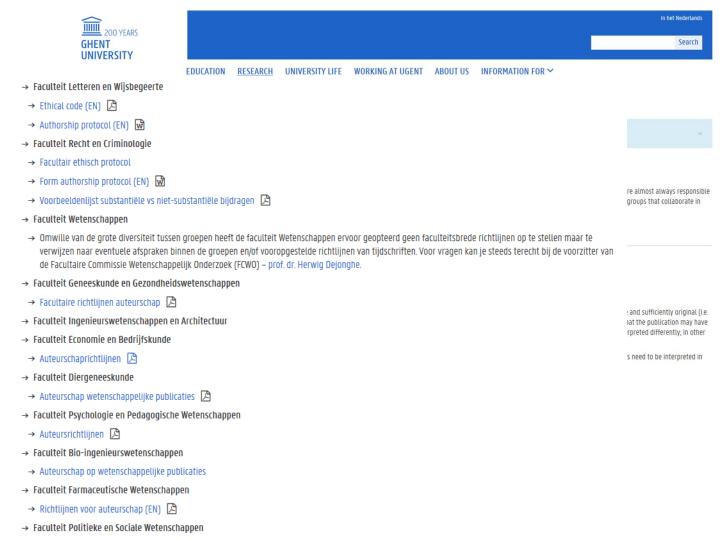
TIPS ON AUTHORSHIP



Source: www.communityfoundation.org.uk

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→ Facultair publicatie-etiquette (EN) 🔀



In het Nederlands Search



Home > Research > For staff > Research policy and organisation > Authorship in scientific articles

On this page

- → Who can be put on the article as (co-) author?
- \rightarrow The order of the authors
- → (Legal and ethical) infringements on authorship rules

Info Je bent aangemeld. Info op jouw maat vind je op de studentensite of op het intranet voor personeel.

Authorship in scientific articles

Today, the traditional publication model of a single author prevails in only a few disciplines. In most other disciplines, multiple authors are almost always responsible for a publication, ranging from the limited partnership between doctoral students and their supervisor(s) to the publications by large(r) groups that collaborate in large international consortia.

Who can be put on the article as (co-)author?

Being an author in a legal sense (in terms of copyright)

The author(s) is/are the person(s) who has/have produced the publication.

A publication is co-authored when the co-authors together, in consultation with each other, have realized a publication which is concrete and sufficiently original (i.e. authentic and creative) to be protected by copyright. Not all authors are required to make the same (large) contribution. What is key is that the publication may have been possible without the contribution of a person designated as an author, but that it would have been different or may have been interpreted differently; in other words, what matters is that the contribution was substantial.

In this approach, there is still room for interpretation, as opinions may differ on what exactly is a substantial contribution. These concepts need to be interpreted in accordance with the ethical regulations concerning authorship in science.

Being an author in an ethical sense





(RE)SEARCH TIPS

Practical tips for research, information management and scholarly communication

SEARCH BY CATEGORY AGENDA

Authorship: 10 best practices

If you are thinking about writing a new publication:

- 1. **Consult** the **guidelines on authorship** within your field and/or faculty and find out what policy is in place at the journal in question. Make sure that any arrangements are always in line with this policy.
- Discuss authorship issues beforehand (i.e. before you start writing) with anyone you want to involve in your publication (e.g. your supervisor, colleagues, experts). Clearly state what role you would like them to take up and what they will get in return. As such, each person involved may point out what their expectations are.
- 3. Use an authorship protocol (e.g. protocol of the Faculty of Law and Criminology, of the Faculty of Arts and Philosophy) to formalize any arrangements made or at the very least record arrangements in an email. The **allocation and order** of authorship is known and **approved by all partners**.
- 4. **Appoint** one **corresponding author** Naturally, this person meets all the criteria for authorship. At the very least, this person has a clear view of how the article was realized and what everyone's contribution was. S/he is also ultimately responsible for all contributions being correctly listed. This person is responsible for the entire content of the article, owns the materials used or knows where to find them (e.g. version control, data) and acts as the official point of contact. When this person is appointed, it is crucial that s/he continues to meet these requirements in the long term; at the very least s/he is required to have fixed contact date, as well as a commitment to follow-up.
- 5. In the course of the publication, certain **changes** are likely to occur (e.g. determined contributions may be altered, an expert may be added). In that case, any **decisions** that were taken will be reviewed and, if necessary, **amended**. + See item 3.
- 6. Journals increasingly require an authorship contribution statement, also known as contributorship disclosure, which explicitly and in detail describes what each author has done to realize the results, ranging from producing the research idea to writing and submitting a publication. Regardless of whether it was specifically requested by a journal, it is recommended that **for each manuscript** a clear description is given of **who was responsible** for what part and **what they did exactly**. These statements are preferably included in the actual article. Make sure that the contributions of all authors are explained in a clear, precise, detailed and accurate manner. Examples of authorship policies: Nature, PLoS, ...
- 7. For each author, add the correct affiliation and ORCID.
- 8. Anyone who **does not meet the criteria** for authorship **but did** somehow **make a valuable contribution** to the manuscript (e.g. by offering an idea, technical support, material, financial support or statistical advice) may be **acknowledged** by being mentioned in the acknowledgements section, in a footnote on the first



ISSUE #2 – PLAGIARISM



SIMILAR BUT NOT THE SAME

A close friend asks me to comment on his paper. While reading the paper I detect a great number of similarities with some recently published papers. The similarities do not constitute plagiarism in a literal sense, but are noticeable. When confronting my friend with my findings he seems unimpressed and submits his paper to an international journal without any profound changes. A couple of weeks later I receive the request from the journal to act as a referee on this particular paper.



WHAT WOULD BE YOUR OPTION?

- A. I decline the invitation.
- B. I accept the invitation but in my review do not mention the similarities I noticed before.
- C. I accept the invitation and report the similarities.
- D. I ask my friend what he wants me to do.



WHAT DOES THE CODE SAY?

<u>EU-code:</u>

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GHFNT

UNIVERSITY

- Authors **acknowledge** important work and intellectual contributions of others, including collaborators, assistants, and funders, who have influenced the reported research in appropriate form, and **cite** related work correctly.
- Researchers **take seriously** their commitment to the research community by participating in **refereeing, reviewing and evaluation**.
- Researchers review and evaluate submissions for publication, funding, appointment, promotion or reward in a transparent and justifiable manner.
- Reviewers or editors with a conflict of interest withdraw from involvement in decisions on publication, funding, appointment, promotion or reward.
- **Ignoring** putative **violations** of research integrity by others or **covering up** inappropriate responses to misconduct or other violations by institutions is considered **misconduct**.

REFERRING TO OTHER SOURCES

QUOTATION

reproduces a statement word-for-word as it appears in its original source

PARAPHRASE

explains a statement by using your own words and sentence structure

SUMMARY

explains a statement using your words, but typically condenses a larger statement into a shorter explanation



Obviously, in a multi-national collaboration, the laws of two or more countries may govern the research. All parties need to agree in advance how compliance with national laws and rules will be assured.

From Boesz, C. C. and Fischer, P. L. (2010) 'International cooperation to ensure research integrity', in M. S. Anderson and N. H. Steneck (eds.) International Research Collaborations: Much to be gained, many ways to get in trouble. New York: Routledge, p.129.

When traicelogists work internationally, they should be cognizant of possible conflicts in national regulations. As Boesz and Fischer note, 'all parties need to agree in advance how compliance with national laws and rules will be assured' (2010, p.120).



Obviously, in a multi-national collaboration, the laws of two or more countries may govern the research. All parties need to agree in advance how compliance with national laws and rules will be assured.

From Boesz, C. C. and Fischer, P. L. (2010) 'International cooperation to ensure research integrity', in M. S. Anderson and N. H. Steneck (eds.) *International Research Collaborations: Much to be gained, many ways to get in trouble.* New York: Routledge, p.129. Boesz and Fischer (2010) recommend that researchers who could orate internationally decide at the outset how they will handle differences in national laws to which their work is subject.



Obviously, in a multi-national collaboration, the laws of two or more countries may govern the research. All parties need to agree in advance how compliance with national laws and rules will be assured.

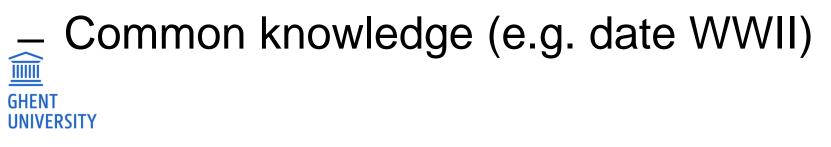
From Boesz, C. C. and Fischer, P. L. (2010) 'International cooperation to ensure research integrity', in M. S. Anderson and N. H. Steneck (eds.) *International Research Collaborations: Much to be gained, many ways to get in trouble.* New York: Routledge, p.129. Physicists who work outside their own countries need to agree in advance how compliance with national laws and rules will be assured (Boesz and Fischer, 2010).



RULES ON PLAGIARISM

- Content (words), structure (composition)
- Ideas (from colleague, journal,...)
- Images (also internet)
- Articles (newspaper, magazine, ...)
- Internet sources
- Translations

NOT:





<u>PLAN – DO – CHECK</u>

- Keep track of (complete) sources and notes carefully, from the start
- Take your time to cite or refer correctly, keep tracking yourself
 + careful with cut/paste
- Practice, practice, practice
- Use an electronic tool (Endnote, Mendeley)
- Always take into account reader's perspective
- Plan! Stick to it!
- Ask for help
- Make it worthwhile





<u>ISSUE #3 – DEALING</u> WITH DATA



FLEXIBLE CRITERIA

A leading senior researcher in my field of interest asks me to work on a project with him. He has already collected the data from fifty randomlyselected organizations and I am working on the analysis. After finalizing the paper together and submitting it, a reviewer points out that only thirty organizations meet our sample selection criteria. Making use of a smaller sample threatens the credibility and validity of the results. The senior researcher is not worried at all and tells me to simply change the sample selection criteria so that they are easily met by all fifty organizations. What do I do?



WHAT WOULD BE YOUR OPTION?

- A. I accept the change in the sample criteria as proposed by the senior researcher.
- B. I refrain from changing the sample criteria and withdraw my name from the paper.
- C. I make sure that the article mentions that the co-author is responsible for the data and methodology.
- D. I perform an additional survey to come up with 20 new companies that meet our criteria. That will take a significant amount of time and delay the project for a few months.



WHAT DOES THE CODE SAY?

<u>BE-code:</u>

 Sampling, analysis techniques and statistical methods should not be chosen or manipulated with a view to obtaining or justifying a result defined in advance.

<u>EU-code:</u>

- Researchers design, carry out, analyse and document research in a careful and well-considered manner.
- Researchers publish results and interpretations of research in an open, honest, transparent and accurate manner, and respect confidentiality of data or findings when legitimately required to do so.
- All partners in research collaborations take responsibility for the integrity of the research.
- All authors are fully responsible for the content of a publication, unless otherwise specified.



I have run an unsuccessful experiment. The results are very different from any of the earlier experiments. I am disappointed because I had carefully designed all the manipulations and stimuli, and the previous (same) experiments that I ran for the same project had worked out. I am now writing the paper.



WHAT WOULD BE YOUR OPTION?

- A. I fully report the failed experiment as one of the main studies in the paper and speculate about the potential reasons behind the unsuccessful results in the discussion section.
- B. I mention the unsuccessful experiment in one sentence and ask the interested readers to contact me for more details.
- C. I do not mention the unsuccessful experiment anywhere.
- D. I leave out the unsuccessful experiment from the paper, but mention it in the cover letter to the editor and suggest it can be included if so desired.



WHAT DOES THE CODE SAY?

<u>EU-code:</u>

• Authors and publishers consider **negative results to be as valid as positive** findings for publication and dissemination.

• Researchers design, carry out, analyse and document research in a careful and **well-** considered manner.

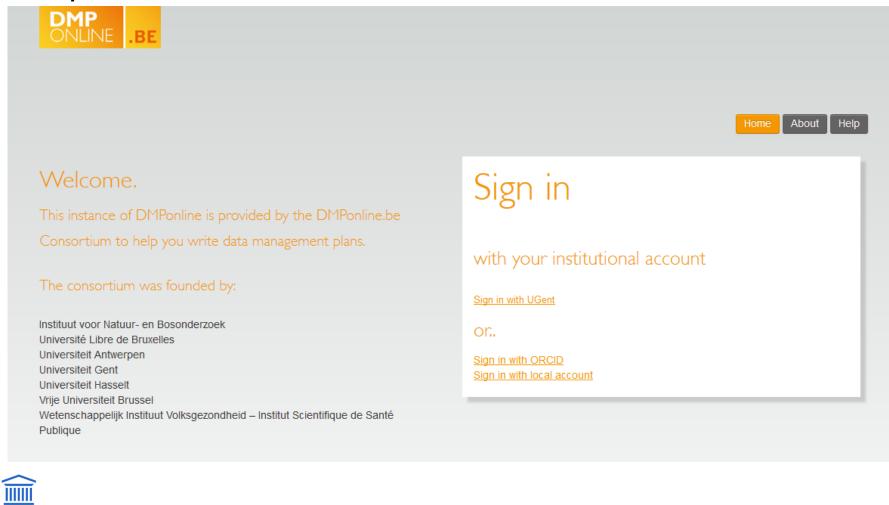
- Researchers publish results and interpretations of research in an open, honest, transparent and **accurate manner**, and respect confidentiality of data or findings when legitimately required to do so.
- Researchers report their results in a way that is **compatible with the standards of the discipline** and, where applicable, **can be verified and reproduced**.
- Withholding research results is considered misconduct.
- Researchers, research institutions and organisations ensure access to data is as open as possible, as closed as necessary, and where appropriate in line with the FAIR Principles (Findable, Accessible, Interoperable and Re-usable) for data management.



MAKE A DATA MANAGEMENT PLAN (DMP)

Templates and tool: DMPOnline.be

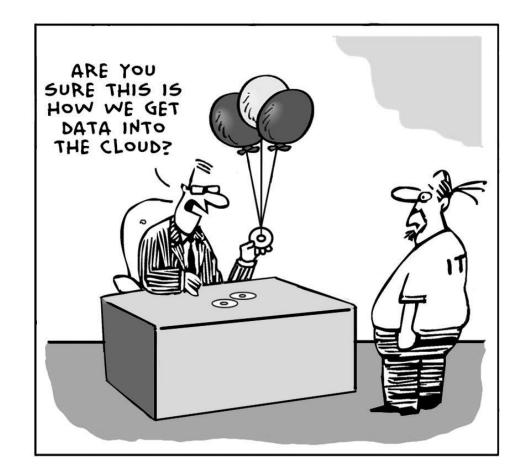
GHENT UNIVERSITY



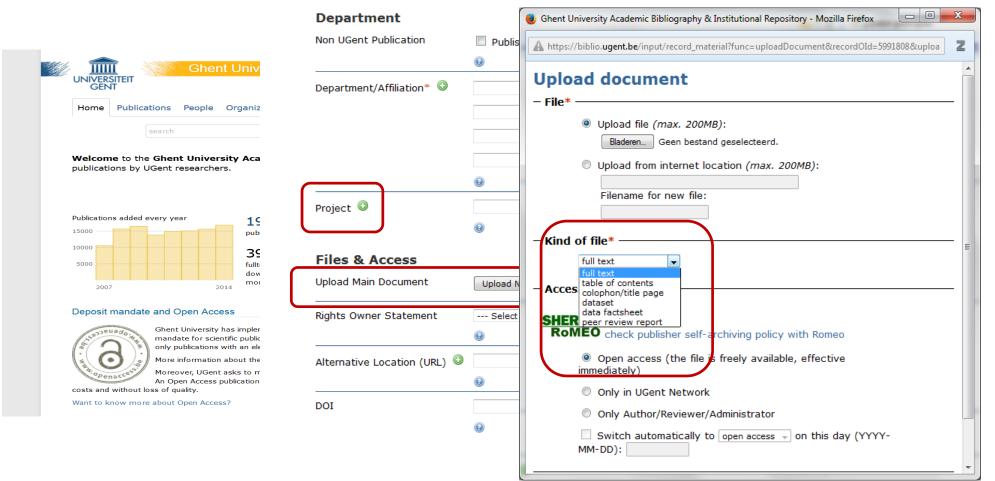
DATA STORAGE – DATA SHARING

Safe long term data storage

- Local storage = RISK
- Central infrastructure!
 - Network drive (H:
 - 'home')
 - Shared directory
 - Sharepoint









<u>ISSUE #4 – POWERS</u> THAT BE



POWERS THAT BE

I was given a research grant at Ghent University to study armed groups in a certain area of an African country. By mapping the groups and activities, I was able to study one group fighting for better human rights quite intensively and could give a full view of their organisational structure, the members, sympathisers and their activities. In some cases these activities contain or relate to non-legal (criminal) activities but I have also discovered the group has good connections to several civil servants. I am writing the final report and preparing my communication strategy.



WHAT WOULD BE YOUR OPTION?

- A. I fulfill my obligations as a PhD student (put it in the UGent repository) but otherwise keep a low profile. I decide not to broadcast my results to any African organisation or government service.
- B. I make a full report of all my findings and send it to anyone I think of that might have an interest.
- C. I write two versions of the PhD; one full version for my promoter at Ghent University and one shortened, more anonymized version to send out to African stakeholders. My recommendations still stand but the groups identity is protected.
- D. I demand a confidential version of my PhD and refuse to write any articles about it.



WHAT DOES THE CODE SAY?

<u>EU-code:</u>

authors ensure that their work is made available to colleagues in a timely, open, transparent, and accurate manner, unless otherwise agreed, and are honest in their communication to the general public and in traditional and social media.
researchers handle research subjects, be they human, animal, cultural, biological, environmental or physical, with respect and care, and in accordance with legal and ethical provisions.

researchers have due regards for the health, safety and welfare of the community, of collaborators and others connected with their research.
researchers recognize and manage potential harms and risks relating to their research.



<u>ISSUE #5 – SHARING</u> <u>BENEFITS</u>



SHARING BENEFITS

For my research project I painstakingly collected an enormous amount of samples coming from different kinds of insect species, some of which are known, some, I hope, will be new discoveries. The idea is to take them back to Belgium and use the specialised lab devices of Ghent University to analyse metabolic pathways related to a specific gene expression and see how this knowledge can be used in the development of new drugs.



WHAT WOULD BE YOUR OPTION?

- A. I take the samples and bring them back to Belgium for testing and further development. I did all the work, I want this to be a possible breakthrough for my career
- B. I ask my local partner if I can take the samples with me and will acknowledge him/her in all articles to come for his help in finding the right spots for data collection
- C. I'm not aware of any regulations and I'm not bothered by it, at least not until there's a realistic potential for developing a new drug. I'll then take a look at it
- D. I ask my promotor if I can use part of his luggage to fit the samples in



WHAT DOES THE CODE SAY?

The Nagoya Protocol on Access to Genetic Resources and the Fair and Equitable Sharing of Benefits Arising from their Utilization to the Convention on Biological Diversity

Link website Ghent University log in – in English





<u>ISSUE #6 – INFORMED</u> <u>CONSENT</u>



BENEFICIAL RESEARCH

For my medical research I have to include at least 20 patients as participants. I have found very few participants so far. It seems very hard to explain my research topic and the goal of the study in layman's terms. Either people have no idea what is expected of them or, the opposite, they immediately expect me to solve all their health issues. This is endangering the deadline we have agreed upon with our external sponsor. They might reconsider their support for our research project. We are not aware of any side-effects and are looking at the possible benefits. In my experience I know that if I oversimplify what we will do, emphasize the potential benefits for their individual situation and stress that there are no side-effects, more people will be willing to participate.



WHAT WOULD BE YOUR OPTION?

- A. I emphasize the benefits to participants for their individual situation, without mentioning side-effects. They don't need to sign the informed consent. A lot of people in this area are illiterate so this gives an acceptable reason not to.
- B. I only mention to participants that they need not worry about side-effects and this will improve their situation. They can sign the full informed consent.
- C. I accept the fact that I will not meet the deadline we have discussed with our sponsor.
- D. I use a smaller group of participants even though this might endanger the significance of some results.







Need info? Check our website!

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