

QUEST Seminar on Responsible Research

Addressing Global Power Asymmetries through Responsible Research: Shared Document

Scholars based in the Global South have long been pointing out that the global research system is characterized by globally unequal conditions in terms of access to resources and recognition. Calls for the decolonization of knowledge production also address the field of health research. Taking up these calls, we will raise the issue of including a global dimension in conceptions of Responsible Research and introduce a critical vision of the power asymmetries that shape implementation processes.



This document is shared during the seminar with the audience for notes, questions, and resources. This document will be available to those who attend the Seminar afterward.

Date: 11/07/2023

Panelists: Muneera Rasheed, Karina Formoso, Paloma Rojas-Saunero

Moderator: Laura Ación

Facilitators: Jesica Formoso, Mariela Rajngewerc, Sabrina López

Organizers: Sarah Wendt, Christiane Wetzel Slides: http://tiny.cc/QUESTSeminarSlides
Teams Link: Click here to join the meeting

Welcome! Please tell us about you

Please add your name and where you are connecting from (optional activity)

Duration: 1 minute

- Jesica Formoso (Argentina)
- Sabrina López (Argentina)
- Mariela Rajngewerc (Argentina)
- Muneera Rasheed (Pakistan)
- Paloma Rojas-Saunero (United States)
- Laura Ación (Argentina)
- Karina Formoso (Toulouse, France)
- Christiane Wetzel (Germany, BIH QUEST Center)
- Fabian Hempel (Germany, BIH QUEST CENTER)
- Mohammed Patel (South Africa WITS University)
- Sarah Wendt (Germany, BIH QUEST Center)
- Karin Höhne (Germany, BIH equal opportunity)
- Uli Dirnagl (Germany, BIH QUEST)
- Romain Faure (Germany, Berlin Center for Global Engagement)
- Anja Collazo (Germany, BIH QUEST Center)



- Katharina Grauel (ECN & NeuroCure, Berlin, Germany)
- Ludmila Litvin (Germany Berlin, BIH QUEST Center at Charité)
- Lorena Martinez Gamboa (Germany, BIH QUEST Center at Charité, Berlin)
- Claudia Mahlke (NeuroCure, Charité, Berlin, Germany)
- Jeanne Wieland (Charitè, Berlin)

Question 1: What Is and Why Do We Need Responsible Research?

In this part, each panelist will tell us what they understand by Responsible Research and why they agreed to be part of the conversation.

Notes:

- Paloma:
 - Responsible research is a way to look at scientific research in an integrative way:
 - It connects with the community the research is supposed to be about.
 - It communicates and engages with the public.
 - It is done in an ethical and accountable way.
 - She joined to discuss power imbalances when we are doing global research
- Muneera:
 - It is research with a long-term goal in mind, beyond academic requirements such as the number of publications.
 - It's about the people and the community we collect data from and how the research will benefit them in the long run. Are these the values that we are looking for? How do we impact these communities?
 - I wanted to be part of the panel today because I think we need to come back to these values, to that innate joy of being curious, of bringing something of impact to these communities.
- Karina:
 - In my field, it refers to:
 - Ethical and intelligent use of animals in the laboratory.



- Scientific integrity in data generation and analysis.
- When we work with patients to be sure that we are providing all the information necessary about the future use of the samples.
- Considering all the people that participate in a project (giving parts of grants, authorship, proper credit).
- Promoting diversity and inclusion.
- Pay attention to local priorities aside from global priorities.
- I think we have to work to make the scientific community a better community. There are many things in which we fall as in sharing, promoting, and studying and I think we need to discuss these issues.

Questions - Please leave us here your questions for this section:

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Question 2: What does the following map evoke to each of you and what tip could you give the audience to equalize this map?

World Scaled by Number of Papers, Web of Science (2016)

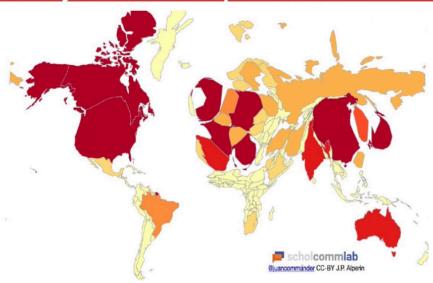


Image: https://doi.org/10.6084/m9.figshare.953177, taken from Sharan https://zenodo.org/record/5518163#.YXnPihrMJPY

In the world scaled by the number of papers, according to the Web of Science, the North is overrepresented. What does this map evoke in each of you, and what tip could you give the audience to equalize this map?

Notes:

- Muneera:
 - When we talk about scientific or global evidence is usually associated with some northern countries, and we apply that to the majority of the population. Particularly in Health, we have imported standards from middle-class American families.
 - We see is what we incentivize. If you are incentivizing the number of papers, you get the map we are seeing. It is a reflection of the resources that these countries have. Should we prioritize the quality of papers rather than just the number of papers?



- How do we equalize it? Right now, the focus is placed mostly on the West to take responsibility to equalize by giving more resources and less in how the researchers in the global majority countries like mine can take responsibility for our people and our communities, that self-determination, and for us to sees the opportunity to build a different system that is not driven by the number of publications. What can be alternative systems and incentives? What alternative ways of mentoring people?

Karina:

- I agree with many of the points Muneera made. I think there are some points that can be changed, for example, the underrepresentation of the global South in editorial boards, because it leads to harsher reviews for authors from the Global South. It is important to value the work and not the part from where we come from and our name.
- Also, journals are reticent to accept subjects that are a local priority and not a
 global priority. For example, in Argentina, Chagas disease affects our region a
 lot, and we have problems publishing subjects on the matter because it is a
 local priority. We have to speak up about this.
- Regarding the language barrier, editorials should be accounted for editorial work: correct the language.
- Global South countries should receive waivers for publications because if the research is important, money should not be a barrier for that work to see the light.

- Paloma:

- I agree with Muneera and Karina.
- This map also resonates with me in terms of looking at Alzheimer's disease research globally. The Lancet Commission has a Review of preventing dementia with the most important modifiable risk factors, which has been used by the WHO to create guidelines that are spread throughout the countries. However, most of the research comes from North Europe and the US. For example, the meta-analysis included in this review regarding hypertension as a risk factor included 20.000 white participants, 31 black individuals, and 2000 Japanese Americans. These numbers were discussed in this work. This shows how biased the research is and how the guidelines that



- we use in clinical practice are focused on white individuals. And in Alzheimer's disease, specifically from educated white individuals.
- This connects to the idea of parachute science, where scientists from the Global North use their resources to conduct research in the Global South, but this is mostly to keep uplifting their own work and prestige in academia and not to facilitate and uplift the needed work in the global south in partnership and supporting the local communities and the local researchers. I want to raise awareness that this is not the solution.

Questions - Please leave us here your questions for this section. Include your name if you want credit for it:

Question 3: What do you think about the story behind this retraction due to an honest mistake? How could this situation have panned out differently for the authors?



Retraction Watch @RetractionWatch · Jun 17

Journal pulls paper from Ethiopia for unlicensed use of questionnaire. retractionwatch.com/2023/06/07/jou...

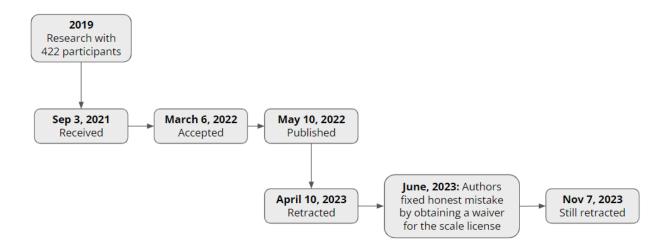
Source: https://twitter.com/zephab2/status/1687266724129951744



PLOS GLOBAL PUBLIC HEALTH

Medication adherence and its associated factors among type 2 diabetic patients in Ethiopian General Hospital, 2019: Institutional based cross-sectional study

Belete Achamyelew Ayele , Sofonyas Abebaw Tiruneh, Asnakew Achaw Ayele, Melaku Tadege Engidaw, Getachew Yideg Yitbarek, Alemayehu Digssie Gebremariam



Sources:

https://journals.plos.org/globalpublichealth/article?id=10.1371/journal.pgph.0000099 and personal communication with the authors

PLOS Global Public Health published this paper from an Ethiopian research group. It passed peer review, and it was a high-quality publication. However, the journal retracted the paper as a preventive measure for the unlicensed use of a questionnaire. The researchers managed to get the license waivered by the original questionnaire's author but the publication remained retracted. What do you think about the story behind this retraction due to an honest mistake? How could this situation have panned out differently for the authors?



Notes:

- Karina:

- The situation is appalling. The main mistake is how PLOS managed the situation. PLOS should have checked this before. Afterward, they should have checked if there was a way to solve this rapidly before getting the paper retracted since the author received the waiver once they were pointed out the copyright infringement.
- I don't know if people realize the toll this has on the authors' reputations and their work because people only see you have a retraction, and there is no justification. The retraction is just for a legal point. The quality of the paper was not in question, and they did not consider the amount of work that a study with almost 500 patients implies. I am disappointed because PLOS sells itself as an inclusive journal.

Paloma:

- This is a clear example of unfair and unethical behavior with authors from underrepresented countries. This reflects the power dynamics in academia that are perpetuating white supremacy. It is sad that this is a global health journal because it had this true mission to uplift researchers from the so-called Global South. It makes me feel in some way that the whole journal or the system is performative around the narratives around Global Health and their allyship. I feel disappointed about that.

- Muneera:

- What I have seen in global health and publishing, it is a multibillion-dollar industry in a capitalist society; it is not about science but about business. This is an opportunity for the Global South to think about having our own platforms, our own global health journals, with people who understand the pain of working with 422 participants. We don't have an army of people writing for us. The people in the north don't understand how hard it is to pull out time for writing, and you have to be very motivated to do this on your own. We need a place where this is understood.



Questions - Please leave us here your questions for this section. Include your name if you want credit for it:

- 70% of scholarly publishing in south america takes place in diamond OA journals.

 Latin america is the pioneer of diamond OA worldwide. I always use this as an example for the things we (global north) can learn from the global south.

 https://www.cnrs.fr/en/cnrsinfo/open-science-international-vision-shared-south-america
- https://www.scielo.org/

Question 4: In her recent **BMJ** piece, Muneera wrote:

"The calls for action should go beyond the notions of equity in research authorship or funding generously granted to us by our colleagues in the Global North, and must recognise that our existence is not solely defined by partnerships. This approach implies that we need to fit into a system that exists in the Global North, even though it may not function in our contexts nor align with our needs."

Muneera, could you tell us more about these interesting concepts? Paloma and Karina, what are your thoughts?

Notes:

- Muneera:
 - I write from experience. I had collaborators from the North who were very clear that they were the *masters*, and that has been said to me clearly, and I also had collaborators who have been very respectful. And what I find is that even when we participate in the decision process, what gets funded in intervention research is all about importing science, how the "poor kids" brains work, or how the mothers in this poor area are getting depressed. Is all about our lives being less worthy, and the intervention that you will be funded for is always going to be a low-cost intervention. The question is what



should be funded. For example, no research on Pakistani middle-class families gets funded. Funding comes from millionaires evading taxes and not believing in equity. We need allies with the right kind of resources and funding. I don't want the Lancet to come up with Lancet regional, I want Lancet editors to tell us how to make a great journal and support us in that enterprise. We have to make them better allies.

- Paloma:

- This resonates with me in a lot of ways. I trained as a medical doctor in Bolivia, but there is no epidemiology degree in the country, so I was forced to leave the country and move to Argentina. Eventually, I found out about all these fancy methods for causal inference, and I had to move again, this time to the Netherlands to do my PhD on causal inference. I was very restricted to do a specific agenda. If I wanted to use these methods for things other than medication, suddenly, they were not suited to ask any other type of questions. The people writing the methods will tell you you cannot use them to study social determinants. When I want to connect these methods to my background, they tell me no: if you want to stay here, you have to use them as is.

Questions - Please leave us here your questions for this section. Include your name if you want credit for it:

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Question 5: In her <u>article for Epidemiology in 2021</u>, Paloma wrote:

"Being involved in projects happening in Bolivia make me aware of how much of the top research published in highly recognized journals cannot be generalized to minoritized populations, and how much is lost when social determinants are not explored."



Paloma, could you tell us more about the projects you were involved with and your learnings? Karina and Muneera, how do Paloma's comments and learnings resonate with you?

Notes:

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Questions - Please leave us here your questions for this section. Include your name if you want credit for it:

- Causal inference in preclinical research by QUEST members: https://www.biorxiv.org/content/10.1101/2023.10.19.560730v1
- I think this note is from Ludmila Litvin. This is Paloma's contact:

 Ip.rojassaunero@ucla.edu https://paloma-rojas-saunero.netlify.app/es/

Survey

Please complete this short anonymous survey to let us know one thing you liked about the seminar and one thing you would change about it. Remember, some useful point on how to give helpful feedback: Be positive, Be specific and Suggest the next step: http://tiny.cc/QUESTSeminarSurvey

Further Reading and Resources

- The case for a Global South centred model in global health. Muneera A Rasheed. BMJ 2023; 383 doi: https://doi.org/10.1136/bmj.p2256
- Navigating the violent process of decolonisation in global health research: a guideline. Muneera A Rasheed. The Lancet Global Health. https://www.sciencedirect.com/science/article/pii/S2214109X2100440X



- In the midst of two realities. Paloma Rojas Saunero.
 https://cdn-links.lww.com/permalink/ede/a/ede 32 1 2020 10 28 swanson 20-078
 2 sdc1.pdf
- Al was asked to create images of Black African docs treating white kids. How'd it go? https://www.npr.org/sections/goatsandsoda/2023/10/06/1201840678/ai-was-asked-to-create-images-of-black-african-docs-treating-white-kids-howd-it-
- Ten simple rules for Global North researchers to stop perpetuating helicopter research in the Global South.
 https://journals.plos.org/ploscompbiol/article?id=10.1371/journal.pcbi.1009277

