Stellenbosch University Library Auditorium, Rooiplein, Tuesday, 21 May 2019, 9:00 to 13:10

Anita S van der Merwe, Professor Emeritus, Faculty of Medicine and Health Sciences, Stellenbosch University

FOCUS: RESEARCH INTEGRITY

"I wish that the colour of our skin does not change and affect where we as women are placed in people's minds, but rather that our character and scars will earn the respect and recognition we so dearly deserve" (Michelle Thomas, SAPeopleNews, May 17, 2019)

INTRODUCTION Α

Race, gender and ethnicity: Complex concepts, take care of flagrant use

- 1. Race is
 - a. A complex and historically loaded construct
 - b. May lead to the "othering" and a hierarchy of "races"
 - c. It should never be routinely and flippantly used
- 2. The construct of race is only defensible as a social category with an explicit social justice focus and must be an interpretation provided by the participant themselves, with a choice to say no, I don't want to ...
- 3. SA:
 - a. Racial categories themselves are questionable and contested and tend to become the focus
 - b. Important to re-interrogate constructs of race and rather focus on the preferred use of socio-economic status (SES)
 - c. Racial categories are often used for bureaucratic and political purposes, should be for social justice and in the context of the critical race theory
- 4. Do not forget gender though, as it is more complex as it seems biological meaning versus social construct
 - a. Man, woman, cisgender (corresponds to as assigned at birth), transgender, etc.
 - b. Sex (biological meaning male/ female)

B IMBEDDED INSTITUTIONAL AND PERSONAL REALITIES WHEN WE REFLECT ON RESEARCH INTEGRITY

Researchers have to and wish to "perform" - Pressured to publish amongst hectic schedules, huge expectations, balancing acts and coping with complex research contexts, historical nuances

- 1. Take in ethically defensive attitude rather than being ethically astute, kind and accommodating - inclusive to consider the REC review process a pain and over-thetop 😳
- 2. May do salami-slicing
- 3. Succumb to superficial and confounding¹ findings
- 4. May be enticed to draw conclusions other than what is supported by the data
- 5. Tend to overgeneralize in the face of insufficient evidence,
- 6. May do selective reporting and make dangerous inferences
- 7. May have limited scientific depth and experience in using certain instruments, or interpreting such data, overconfident in stating such findings
- 8. May not deeply and carefully provide descriptors, nor see associated problems

¹ Distortion, inaccuracy, for example in deducing the cause-effect relationship.

- 9. On the other hand, researchers may include a focus on racial and ethnic differences but then simply leave such out when findings do not support such differences; even though it was a central motivation for the initial study
- 10. Pressure of power groups for example 1993 guidelines US National Institutes of Health (NIH): Mandated proportionate representation of patients by race and ethnic group in clinical research they fund for a good reason though...
- 11. Lastly, but very importantly: May be scientifically arrogant and not really know enough I refer to the Dunning-Kruger effect: cognitive bias, do recognize deficits. Do we really know how a helicopter works?

C RESEARCH ETHICS

Justice

1. Focuses on treating everybody the same; rendering what is due, adequately, fairly, impartial, and with full appreciation. Justice relates to for example the fair representation of facts, listening to both sides and managing disputes. It also relates to an individual virtue (a character trait valued as good), to the meaningful order of society and/or to individual rights in contrast to the claims, expectations and deeds of the wider society.

Integrity

Integrity stems from the Latin word "integrita" - wholeness or completeness and refers to a moral ideal. Integrity encapsulates the meaningful, mature and coherent wholeness between espoused values and actions. It accepts:

- a. A willingness and commitment to stand for and act for such values, and
- b. Responsibility to deal with/ manage the consequences of standing for such values
- c. A truly integrated person with integrity will find, nurture and manage links between espoused values, such as between honesty and fairness or between beneficence and non-maleficence.

Research integrity

Refers to quality of having and applying critical moral principles as outlined by the scientific endeavour, the profession we are part of, the communities we serve, and public and regulatory institutions.

It is essentially about instilling **trust** in the science we produce. It is however important to remember that **research integrity is imbedded in a whole ecosystem** of researchers, publishers, participants, communities, and importantly also, institutional inputs, processes and outcomes.

D IMPORTANT CONSIDERATIONS IN RESEARCH INTEGRITY - the questions to ask:

- 1. Social value of research the more vulnerable participants are, the more important to do meaningful research. Very important: Local social value.
- 2. Who is the researcher where do I come from, what is the lens I look through? Researcher positionality and truthfulness
- 3. The critical detail for example
 - a. Describe sample to answer specific research question explain rationale, sample size intricacies to deduce findings
 - b. Instrument used does it fit, is it scientifically defensible in context?
 - c. Need to be clear to all involved: Why is the question about race even asked what is the purpose, to what benefit?
 - d. Participants:
 - i. Provide informed consent
 - ii. Answer willingly and freely
 - iii. Self-identify if racial cluster is used and if necessary at all!

iv. Have the option: Prefer not to answer!

NB: All demographic questions to aid a social analysis, not a racial analysis.

E RESEARCH ETHICS COMMITTEES

- 1. **Committees exist and consist of you and me** academics and researchers who truly care about scientific and ethical integrity.
- 2. **RECs are inadequately supported** both with infrastructure and financial support. This is seen contradictory to an institutional push of a research-intensive university. We know that experienced and knowledgeable research integrity support is increasingly important in contemporary academic society to develop and enhance research integrity, but to also prevent and, if necessary, manage research integrity fallouts.
- 3. Research ethics committees are **not the police force of science**, but the gentle gatekeepers of sound scientific and ethical research as planned to protect participants; thus the wellbeing and dignity of participants = primary concern
- 4. REC scrutiny is primarily a **social discursive practice** to encourage accountability of researchers.
- 5. **RECs follow structured and disciplined processes** as outlined by national and international guidelines (for example NDOH guidelines 2015) this guideline by the way mentions race only twice and within the context of the SA constitution:
 - a. **Must be necessary to collect this data:** "Information about a person's race or ethnic origin must be necessary (s 29(a)) or for affirmative action purposes (s 29(b))";
 - b. Nobody may be excluded based on race, etc.; or unfairly targeted:
 "Persons should not be excluded unreasonably or unfairly on the basis of any of the prohibited grounds for discrimination: race, age, sex, sexual orientation, disability, education, religious belief, pregnancy, marital status, ethnic or social origin, conscience, belief or language (s 8 of the Constitution). Similarly, persons should not be unfairly targeted for research merely on the basis of one or other of these grounds".
- 6. **Reviewers can only careful review what is presented to them** carefully scrutinizing and deliberating core and key elements of the protocol, inclusive of methodology, sampling, informed consent and instruments as included
- 7. The socio-demographic category of race is often included in many such studies as a self-espoused statement of the participant and with a choice not to respond to such
 - a. Acknowledge that the socio-demographic category of race is a real and sensitive issue, researchers to carefully consider race as a construct and variable why necessary, if acceptable to the participants, right not to respond to such questions per se
- 8. Scrutinise bona fides of researchers (CV's), especially principal investigator
- 9. REC cannot take direct bona fide responsibility for the resultant research process and publications coming forth from such a study (research roll-out) - freedom to publish is an academic work without interference
- 10. Approved versus published: When a REC becomes retrospectively aware, they will immediately compare what was formally planned (protocol) and what was published as outcomes this would then become the essence of a research integrity investigation.
- 11. Deal consistently with **highly sensitive and complex protocols**, some of which that have gone through taxing review panels (such as PhD's)

In the **politics of institutional history, research and researchers' attributes**, this may become a highly polarized event. However, **this polarization is important** in the greater scheme of things - in the spirit of those we care for deeply, the science we profess and the ethical conduct we cherish, reflect on what we need to do better and different.

F WAY FORWARD - CORE PRINCIPLES

Learn from others, for example recent publication (2019 - see reference at end of document) describes the work of a consortium of scientists who put forth two principles and nine best practices to enhance scientific integrity. In summary: **Principles**

(1) Foster culture of integrity in the scientific process

(2) Ensure that evidence-based policy interests do not interfere with scientific integrity.

Nine best practices for instilling scientific integrity in the implementation of these two overarching principles are

(1) **Require universal training** in robust scientific methodologies, statistics, responsible research practices for scientists at all levels, training content to be regularly updated and presented by qualified scientists.

(2) **Strengthen scientific integrity oversight and processes** throughout the research continuum with a focus on training in ethics and conduct - NB, it is critical to revert funds to support the notion of a research-intensive university.

(3) Encourage reproducibility of research through transparency.

(4) Strive to **establish open science** as the standard operating procedure throughout the scientific enterprise.

(5) Develop and implement educational tools to teach **communication skills** that uphold scientific integrity.

(6) Strive to identify ways to further strengthen the peer review process.

(7) Encourage scientific journals to publish **unanticipated findings** that meet standards of quality and scientific integrity.

(8) Seek **harmonization and implementation among journals** of rapid, consistent, and transparent processes for **correction and/or retraction** of published papers.

(9) Design rigorous and comprehensive **evaluation criteria** that recognize and reward the highest standards of integrity in scientific research (Kretzer, et al., 2019)²

² Kretser, A; Murphy, D; Bertuzzi, S; Abraham, T; Allison, DB; Boor, KJ; Dwyer, J; Grantham, A; Harris, LJ; Hollander, R; Jacobs-Young, C; Rovito, S; Vafadis, D; Woteki, C; Wyndham, J; Yada, R. 2019. Scientific Integrity Principles and Best Practices: Recommendations from a Scientific Integrity Consortium. *Science and Engineering Ethics*, 25:327–355; https://doi.org/10.1007/s11948-019-00094-3