



ARESA

NEWSLETTER

ADVANCING RESEARCH ETHICS
TRAINING IN SOUTHERN AFRICA


Stellenbosch
UNIVERSITY
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UNIVERSITEIT


THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL

Volume 13 | December 2023

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Dear REC Members

We are delighted to share this issue of the ARESA Newsletter with you. The 11th Annual ARESA Research Ethics seminar was held at the Vineyard Hotel in Newlands on 13 October 2023. The seminar was themed: Stakeholder Engagement in Data-Intensive Research and encompassed pertinent topics related to Data Science and Ethics. Various regional, national and international speakers and delegates joined the discussions as well as many of our ARESA graduates (2011-2017) and doctoral candidates.



HIGHLIGHTS FROM SEMINAR

This year, 68 delegates from various Southern Africa Research Ethics Committees (RECs) attended the in-person annual seminar. There were 3 plenary sessions: **Researchers' Perspectives on Data-Intensive Research, Stakeholder Engagement the Crowdsourced Way and Data Terminology and Icons: Redesigning Informed Consent Forms**. Following each session, lively interactive panel discussions took place.

PLENARY SESSION 1: RESEARCHERS' PERSPECTIVES ON DATA-INTENSIVE RESEARCH

The first plenary session was chaired by **Emeritus A/Prof. Sharon Kling**. The panel discussion was led by **A/Prof. Joseph Ochieng**, **Dr. Jyothi Chabilall** and **Ms. Qunita Brown**.

A/Prof. Ochieng discussed genetics and genomics research (GGR) and how testing creates unique ethical, legal, and social challenges, particularly the return of results following GGR in low-resource settings. He further explained that, apart from H3Africa guidance, there are no context specific ethics guidelines to facilitate GGR in Uganda. He cautioned that the practicalities of returning results, conditional release of clinically significant and actionable results and participant volition require careful balancing in ethics guidance related to return of GGR results.



Dr. Chabilall presented the views of South African researchers on data sharing opportunities and challenges extracted from a qualitative study conducted. She explained how regulated processes encourage researchers to share data confidently and that innovative technology and well-regulated systems have yielded constructive data sharing. She highlighted that when there is clarity, understanding and acknowledgement, researchers will be optimistic about data sharing collaborations, thus generating multifaceted achievements.

Ms. Brown explored the perspectives of researchers in the sub-Saharan African (SSA) region regarding the challenges associated with data sharing in data-intensive research through semi-structured interviews. Her findings highlight that resources are urgently needed to improve quality, value and veracity of data. She further recommended that developing robust guidelines are imperative to promoting responsible data sharing amongst researchers in SSA.

(Rapporteur: Ms Nezerith Cengiz)

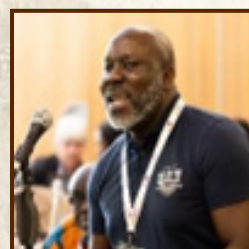
PLENARY SESSION 2: STAKEHOLDER ENGAGEMENT THE CROWDSOURCING WAY

The second plenary session titled "Stakeholder Engagement the Crowdsourced Way" was chaired by **Prof. Stuart Rennie**. The panel discussion was led by **A/Prof. Suzanne Day**, **Dr. Karel Caals** and **A/Prof. Wim Delva**.

A/Prof. Day highlighted the role of community engagement in reducing opacity, preserving trust, and including public interest in the use of big data. However, the barriers to achieving public involvement included lack of data literacy and transparency thus widening gaps between experts and lay persons. Crowdsourcing maybe an effective strategy as it is inclusive with a bottom-up approach to problem solving using community driven solutions. This participatory method facilitates improved understanding of the values, ideas, and experiences of the community.

Dr. Caals highlighted the lessons gained from using social media platforms for raising awareness of this project and the yields gained from Twitter, LinkedIn as users targeted were 18 years and older. Use of any platform requires people to follow one and the content influences the number of followers. **A/Prof. Delva** explained that the use of electronic records in health needs to be advocated among patients so that they understand their rights and role in consenting to data sharing. Educational tools may include storyboards with short messages with images that facilitate understanding.

(Rapporteur: Mrs Neetha Morar)



PLENARY SESSION 3: DATA TERMINOLOGY AND ICONS: RE-DESIGNING INFORMED CONSENT FORMS

The third plenary session was chaired by **Prof. Walter Jaoko**. The panel discussion was led by **Dr. Lillian Omutoko**, **Prof. Shenuka Singh** and **A/Prof. Theresa Burgess**. The final plenary session commenced with **Dr. Omutoko's** presentation on "Dealing with linguistic diversity in processing informed consent in data-intensive research: From the African lens". **Dr. Omutoko** highlighted that most countries in sub-Saharan Africa are multilingual and heterogeneous thereby adding complexities to the informed consent process. The terminology used in data-intensive research, such as data sets, big data, data subjects/donors, data protection, and data controllers may also be unfamiliar to research participants. **Dr. Omutoko** concluded by providing recommendations for informed consent forms for data-intensive research.

Prof. Singh then led an interactive session with delegates where they were requested to share their perspectives on data sharing through Mentimeter. Delegates engaged in a group activity where they were requested to sketch icons for common terms in data-intensive research.

A/Prof. Burgess concluded the session by providing a short summary of iconography. The utility of icons as a mechanism to enhance research participants' understanding of all research, including data-intensive research, was highlighted. It was also recommended that icon design should use the most obvious standardised symbology or metaphor, rather than risking something more unique and having a higher potential of confusing research participants.

(Rapporteur: A/Prof Theresa Burgess)



CONCLUSION

This ARESA seminar was a successful event and was the 11th seminar since the launch of the project. Fruitful discussions took place around data ethics considerations for Data Access Committees (DACs); the use of crowdsourcing to co-create data science educational tools as well as the development of a harmonised data science terminology and understanding of this concept across Africa.

Thank you to all attendees and speakers!
See you at the next ARESA seminar.

ACKNOWLEDGEMENTS

ARESA Funding: The NIH (Award Nr: D43 TW01511-01 / UO1HG008222)

Audio-Visual Services: On Screen Presentations, **Mr. Mohammed Jaffer**

Social Media Marketing: **Dr. Karel Caals**, National University of Singapore

Photography: Expressions Photography

Venue and Catering: The Vineyard Hotel, Newlands

Printing and Banners: African Sun Media

Organising Committee: **Prof. Keymanthri Moodley** (Host & PI); **Prof. Stuart Rennie** (Co-PI); **Emeritus A/Prof. Sharon Kling** (Co-Investigator);

Ms. Nezerith Cengiz (Researcher); **Mrs. Siti Kabanda** (Research Assistant);

Ms. Qunita Brown (Research Assistant); **Ms. Michelle Padiachee** (Admin

Officer); **Mrs. Celeste Youle** (Admin Officer) & **Ms. Rozetta Davids** (Admin

Officer).



ARESA ALUMNI NEWS

Prof. Shenuka Singh was recently appointed as the vice chair of the National Health Research Ethics Council (NHREC). We are very excited for and proud of Prof Singh.

A/Prof. Joseph Ochieng will be graduating this December with his PhD (Clinical and Research Ethics) and **Mr. Francis Masiye** will be graduating in March of 2024 with his PhD (Clinical and Research Ethics). We are very proud of both **A/Prof. Ochieng** and **Mr. Masiye** after all their hard work.

UPCOMING CONFERENCES



CIECC/SCB 2024 ICCEC/CBS
Partenariat avec les patients et les communautés
Partnering with patients and communities
29-31 mai 2024 | May 29-31, 2024

18^e Conférence internationale sur l'éthique clinique et la consultation
32^e Conférence annuelle de la Société canadienne de bioéthique

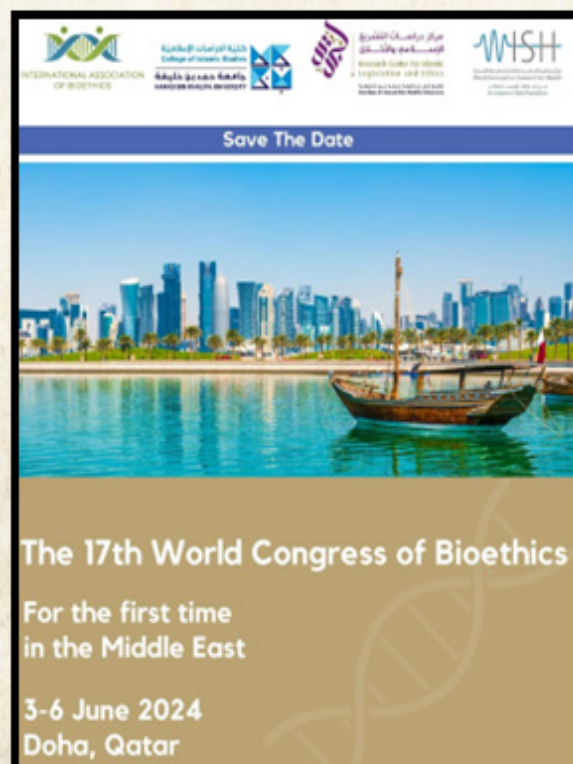
18th International Conference on Clinical Ethics and Consultation
32nd Annual Conference of the Canadian Bioethics Society

Montreal, Quebec, Canada
Partners: Hôpital Ste-Justine, Hôpital Ste-Justine, Hôpital Ste-Justine

Hosted by: **Ethique clinique**
Organisé par: **Ethique clinique**

Partenaire de recherche: **Université de Montréal**

Partners: **ICCEC-CBS**
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Save The Date

The 17th World Congress of Bioethics
For the first time
in the Middle East
3-6 June 2024
Doha, Qatar