ANNOUNCEMENT OF PROGRESS ON THE POPIA CODE OF CONDUCT FOR RESEARCH AND CALL FOR SUBMISSIONS OF ISSUES TO BE ADDRESSED BY THE CODE

In South Africa, the use of personal information for research is regulated by the National Health Act No 61 of 2003 and its 2012 regulations, the Department of Health Ethics in Health Research: Principles, Processes and Structures Guidelines and the Promotion of Access to Information Act (PAIA) No 2 of 2000. The Protection of Personal Information Act (POPIA) No 4 of 2013 came into force on 1 July 2020 [https://www.justice.gov.za/inforeg/docs/InfoRegSA-POPIA-act2013-004.pdf]. All public and private bodies that are processing personal information have until 1 July 2021 to ensure that they are compliant with the law.

Overall POPIA is welcomed as it gives greater guidance to researchers regarding the use and protection of personal information for research purposes. This should serve to improve transparency, accountability and oversight in the processing of personal information and promote public trust in the use of personal information in research contexts. However, there is uncertainty and need for further guidance on the application of the POPIA relevant to research.

ASSAf has engaged with scientists and other stakeholders around developing a POPIA Code of Conduct for Research to ensure certainty, transparency, and clarity in the processing of personal information for research purposes. Although ASSAf considers that it is imperative to have one Code to guide the use of personal information for research in all sectors (including health, social science, genomics, etc.), this does not prohibit other stakeholders to also compile a Code.

ASSAf is now facilitating the process to develop a Code of Conduct for Research, having hosted two stakeholder events that were attended by scientists and researchers from diverse disciplinary backgrounds, such as genomics, biobanking, ethics, and law. We have set up a Steering Committee to oversee the process of developing a Code of Conduct under POPIA for research, as well as a Drafting Committee who will draft the document.

We are now inviting the scientific community to send us lists of issues regarding the processing of personal information for research purposes, or the governance thereof, that the Steering Committee should consider in the POPIA Code of Conduct for Research. In particular, it would be helpful to receive recommendations as to how the Drafting Committee could address the issues raised.

Please send your inputs by 12 February 2021 to Ms Mmaphuthi Mashiachidi (email: mmaphuthi@assaf.org.za).

This is an inclusive process, and a draft of the submission will be circulated to the scientific community for comments and their inputs. This will be followed by another stakeholder meeting before the draft is finalised. The dates for these events will be circulated at a later stage.
The final version will be submitted to the Information Regulator for approval on behalf of the research community before the end of June 2021 deadline.

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