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HOW TO CITE:

Thaldar D, Kinderlerer J, Soni S. An optimistic vision for biosciences in South Africa: A response to the ASSAf report on human genetics and genomics. *S Afr J Sci.* 2019;115(7/8), Art. #6146, 1 page. <https://doi.org/10.17159/sajs.2019/6146>

ARTICLE INCLUDES:

- Peer review
- Supplementary material

KEYWORDS:

Constitution; regulatory environment; health care; ubuntu

PUBLISHED:

30 July 2019

An optimistic vision for biosciences in South Africa: A response to the ASSAf report on human genetics and genomics

The Fourth Industrial Revolution is upon us. One of the pillars of the Fourth Industrial Revolution is the biosciences. What will South Africa's role be in the new global bio-economy?

Our vision for South Africa is to have a vibrant bioscience research community that competes with the best in the world; a bioscience research community that is inspired to develop cures for diseases and improve people's lives; a bioscience research community that is attuned and responsive to local healthcare needs.

How can this vision be brought about? The answer is multifaceted, but includes a *regulatory environment* that is conducive to realising this vision. Such a regulatory environment must first and foremost be legally and ethically aligned with the Constitution. This means that the bioscience regulatory environment must give proper weight to, *inter alia*, the rights of research participants, the rights of researchers, and everyone's right of access to health care – and establish a reasonable balance between relevant rights.

Recently, the Academy of Science of South Africa (ASSAf) published a report¹ entitled *Human Genetics and Genomics in South Africa: Ethical, Legal and Social Implications*. The objective of this report was to inform the genetics and genomics regulatory environment in South Africa. But, is the ASSAf report itself legally and ethically aligned with the Constitution? We must express our reservations.

Although we commend the ASSAf report's engagement with the value of ubuntu, the lack of specificity in terms of which the ASSAf report interprets ubuntu is problematic. There are a variety of interpretations of ubuntu, with some being vague or otherwise questionable guides for public policy. For example, the ASSAf report mentions that, by some understandings of ubuntu, 'the task of the individual is to maintain a good relationship with the visible and the invisible worlds', the latter including the 'living-dead'. Such interpretations of the nature of reality and of how to live one's life are highly contested grounds for public policy in a pluralist, multicultural society such as South Africa. Repeatedly describing the ASSAf report as a 'consensus study' and 'consensus report' threatens to mask the real disagreements that may legitimately exist in our society. By positing ubuntu as a central value for informing the genetics and genomics regulatory environment in South Africa, but failing to propose a clear and specific interpretation of ubuntu, the ASSAf report offers a vague and confused vision for bioscience in South Africa.

Moreover, from a constitutional perspective, ubuntu can assist as a lens through which rights are interpreted, but cannot be a substitute for proper legal analysis of relevant constitutional rights. Although the ASSAf report makes several references to the Constitution and to rights, its legal analysis is thin. This is reflected in the fact that only four legal cases are cited in the entire 125-page report. It is especially worrying that the ASSAf report did not even mention the *constitutional right to freedom of scientific research*. How can ASSAf explain this cavernous omission?

The flourishing of our bioscience researchers is an essential part of our vision for a vibrant bioscience research community in South Africa. Moreover, the flourishing of our bioscience researchers is a human rights issue: If we take our Constitution seriously, the freedom of scientific research of bioscience researchers must be taken seriously, and considered *together* with other relevant rights and values.

The ASSAf report draws an analogy between people's genetic information and natural resources like water and minerals. The ASSAf report even refers to people's genetic information as 'genomic resources'. In what way is an individual's genetic information (something *personal*) the same as water or minerals (something *impersonal*)? This analogy is not only flawed, but dangerous. The ASSAf report proceeds to recommend that the *state* should manage the 'exploitation, protection, sustainability, and fair access to' these 'genomic resources'. Why should the state control the use, in research, of an individual's genetic information? It is hard to see how this proposed state control of individuals' genetic information can ever be squared with the individual's constitutional rights to human dignity and privacy. This natural-resource view of people's genetic information proposed by the ASSAf report reduces the individual to a mere carrier or container of a state-controlled resource. This dystopian vision offered by the ASSAf report undermines its ethical and legal credibility.

The state control of individuals' genetic information proposed in the ASSAf report appears to be based, at least in part, on the simplistic and incorrect characterisation of collectivism as being more authentically 'African' than individualism. Contemporary African value systems are diverse and not monolithic, and are dynamically evolving. The ASSAf report appears to conflate humaneness with collectivism. These are two completely different concepts. A collectivist state may strive to be humane, but also may not. History abounds with examples of inhumane collectivist states. Conversely, states that uphold individualism – the moral worth of the individual – can simultaneously strive to promote the value of humaneness amongst its people and in its law. Is this not the Constitution's aspiration for South Africa?

Will South Africa ride the wave of the Fourth Industrial Revolution? Will our regulatory environment be an effective launchpad for responsible, world-class bioscience research in South Africa? There are many factors that impact on this question, but here we make a simple, perhaps obvious, point: the development of South Africa's bioscience regulatory environment needs to be informed by thorough analysis of legal authority, and a balanced consideration of relevant constitutional rights and values. Sadly, the ASSAf report fails, in a fundamental way, to provide either of these. In contrast with the bleak vision offered by the ASSAf report, we offer an *optimistic* vision – a vision that is aligned with the individual freedoms and rights protected in our Constitution.

Reference

1. Academy of Science of South Africa (ASSAf). Human genetics and genomics in South Africa: Ethical, legal and social implications. Pretoria: ASSAf; 2018. <http://dx.doi.org/10.17159/assaf.2018/0033>