

An optimistic vision for biosciences in South Africa: Reply to Thaldar et al. (2019)

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 Supplementary material

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Our reply to Thaldar et al.'s¹ response to the ASSAf report² on human genetics and genomics focuses on two elements of the Report which they highlight, namely ubuntu and sovereignty. The lack of engagement with other issues raised by Thaldar et al. does not acknowledge agreement with those views.

Ubuntu

Thaldar et al. state that there is no role for the value of ubuntu in the era of the Fourth Industrial Revolution; that the concept, insofar as it reflects African values, as presented in the ASSAf report, is either vague or provides questionable guidance for public policy. The undertone to this assertion appears to be that African values have no relevance in the Fourth Industrial Revolution era, particularly for competing against the best in the world.

We hold a different view as was expressed in the Introduction to Respect for Persons (p.42) where we note that 'respect for persons requires that the interests and rights of both the individual and the collective, specifically those relating to autonomy, privacy, confidentiality and access to the benefits arising from research results, are recognised and protected in a balanced, reasonable and justifiable manner'. Further, the notion of 'relative solidarity' appears to have been misconstrued by Thaldar et al. The recent article by Ogunrin et al.³ was referred to in the Report to emphasise that generalisations, including those about ubuntu (p.41), are undesirable. Ogunrin et al. describe empirical research conducted in Nigeria which found that younger people and urban populations may value self-interest and individual rights more than the common good approach, espoused in the traditional concept of ubuntu. We acknowledge that neither South Africa nor the African continent is culturally homogeneous.

Sovereignty

A consensus study will provide a consensus if one can be reached and, where this is not the case, differing views are presented. The sovereignty issue illustrates a topic that did not lead to consensus. Thaldar et al. have, however, limited their comments to only one section of the discussion on this topic i.e. that presented on p.85 and p.86.

On p.85, we suggest that the State might take responsibility for 'providing the infrastructure to govern and manage access to and (re)use of samples and data', and we draw an analogy with 'the notion of State custodianship (similar meaning to stewardship) of natural resources'. We then point out that 'infrastructure and governance systems are designed to manage exploitation, protection, sustainability and fair access to those resources and a form of redistribution or benefit sharing'. We conclude by noting that: 'There is no obvious reason, thus, why stewardship of genomic resources should not successfully recognize sovereignty over genomic resources in light of stewardship principles'. A number of other views are presented in the paragraphs that follow. The 12th recommendation at the end of the section (p.91–92) provides a balanced consensus view on this complex topic in which we recommend the following:

Debate, explore and adapt the 'sociologically informed model' for the principles of (a) custodianship/ownership of samples and (b) benefit sharing in South Africa. Include relevant stakeholders like the National Intellectual Property Management Office (NIPMO) and the South African Law Reform Commission, since the topics affect a cascade of implications: ethical values of equity and distributive justice; good governance principles of benefit sharing; whether intellectual property can exist if genomic resources are to be regarded as a 'common good'.

We welcome critical engagement by others with the contents of the ASSAf report. Readers are encouraged to read and assess the Report in its entirety.

References

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