



Steve Biko

Centre for Bioethics

Identifying Basic Principles for Moving Forward

Second International Summit on Human Genome Editing

Professor A Dhai
Director Steve Biko Centre for Bioethics
Faculty of Health Sciences
University of the Witwatersrand, Johannesburg

- WHO Health (1948)
 - State of complete physical, social and mental wellbeing, and not merely the absence of disease or infirmity
- UNESCO - Universal Declaration on Bioethics and Human Rights (2005)
 - person's identity includes biological, psychological, social, cultural and spiritual dimensions

Outline

- Principles from latest reports
- Norms and standards

Principles: National Academies Report (2017)

- promoting well-being
 - beneficence/nonmaleficence,
- transparency
 - open sharing of information,
- due care
 - careful approach,
- responsible science
 - highest standards,
- respect for persons
 - all people have equal moral value,
- fairness
 - equitable distribution of risks and benefits, and
- transnational cooperation
 - respecting different national policies, coordination of regulatory stds, data sharing.

Principles: Nuffield Council Report (2018)

- “Principle 1: the ‘welfare of the future person’
 - Gametes and embryos that have been subject to genome editing procedures (or that are derived from cells that have been subject to such procedures) should be used only where the procedure is carried out in a manner and for a purpose that is intended to secure the welfare of and is consistent with the welfare of a person who may be born as a consequence of treatment using those cells. Moreover, the intervention must also be consistent with the welfare of such a person.”
- “Principle 2: Social justice and solidarity.
 - The use of gametes or embryos that have been subject to genome editing procedures (or that are derived from cells that have been subject to such procedures) should be permitted only in circumstances in which it cannot reasonably be expected to produce or exacerbate social division or the unmitigated marginalisation or disadvantage of groups within society.”

- **Responsibility**
 - Not a discrete event but a state that prevails along with the consequences of the decision (NC)
 - person making decision bears responsibility for bringing about state of affairs that result from that decision
- **Accountability**
 - “process in which a person has a potential obligation to explain his/her actions to another party who has the right to pass judgment on those actions and to administer potential positive or negative consequences in response to them” (Vance, Lowry and Eggett 2015).
- Safety, risks, harms, uncertainty – patient, research participants (parents, child (intergenerational), families& society (transgenerational))
- Intergenerational justice – responsibility to welfare of future generations

- UNESCO - Universal Declaration on Bioethics and Human Rights (2005)
 - progress in science and technology contributes to justice, equity and to the interest of humanity
 - Gene rich and gene poor – undermine genetic solidarity
 - Equity and access – corporate social responsibility & meaningful PPP
- Trust & trustworthiness
 - belief in & deserving of trust
- Caring
 - natural striving to relieve sorrow and misery and to transform environment so life becomes liveable and human
- Respectful Public Engagement

- **Governance: Harmonization**
 - Respect differing transnational laws & policies
 - Safeguard against movement of ethically contentious practices to more accommodating regulatory environments - “safari research”

- **Governance: Harmonization**
 - Several UNESCO instruments on the human genome.
 - International instruments and local application – divergence
 - **Report of the IBC on Updating Its Reflection on the Human Genome and Human Rights (2016)**
 - ***States and governments are called on to:***
 - Renounce the possibility of acting alone in relation to engineering the human genome and ***accept to cooperate on establishing a shared, global standard for this purpose***

- **Governance: Harmonization**

- No international treaty of general application directly regulating human genome or possibilities for its modification.
- International law - if state signs a treaty, it is bound to comply with it and has a positive obligation to modify its domestic legislation.
- Need a United Nations Treatise / Covenant on human genome.