

April 2021

Choose as many statements as are correct per question. Some questions may have more than one correct answer – select all that are applicable.

How can research ethics committees help to strengthen stakeholder engagement in health research in South Africa (SA)? An evaluation of REC documents

1. A review of publicly available documents from SA) research ethics committees (RECs) highlighted missed opportunities to prompt researchers to plan engagement in a way that aligns with ethics guidelines. Which of the following were identified as the 'missed opportunities'?
 - a) not explicitly referring to 'stakeholders' broadly
 - b) focusing too much on obtaining gatekeeper permission
 - c) not encouraging engagement throughout the lifecycle of the study
 - d) asking researchers to secure permission from institutional gatekeepers to collect data.
2. Which of the following is *not* a recommended strategy for RECs to improve their documents in a way that facilitates better stakeholder engagement in health research?
 - a) harmonising their stance regarding engagement across their documents, for example, by ensuring that application forms reflect the view in standard operating procedures
 - b) insisting that all studies have a community advisory board
 - c) amending their application forms to prompt researchers to plan stakeholder engagement in a way that aligns with ethics guidance
 - d) amending their renewal forms to ask about engagement activities in the preceding year.

Legal issues in posthumous conception using gametes removed from a comatose male: The case of Ex Parte SN

3. What were the main legal issues the court had to consider in Ex Parte SN?
 - (i) whether posthumous conception is legal in SA
 - (ii) whether gamete removal may occur where the person from whom the gametes are being removed is unable to consent
 - (iii) whether gametes removed from a person who is comatose – and therefore unable to consent – can be used for posthumous conception
 - (iv) whether the applicant (SN) was the legal guardian of the comatose male.

Choose the correct combination:

- a) *i* and *ii* are correct.
- b) *ii* and *iii* are correct.
- c) *i* and *iii* are correct.
- d) *i* and *iv* are correct.

4. Which of the following are arguments commonly raised against posthumous conception?

- a) Posthumous conception is harmful to children because children are harmed by being born into a single-parent household.
- b) Posthumous conception is harmful to children because being deprived of knowing one's parent is psychologically harmful to a child.
- c) Posthumous conception is harmful because children will grow up not knowing their genetic origin.
- d) Posthumous conception is harmful to children because children are harmed by not being able to inherit from the deceased's estate or not being able to collect survivor benefits.

The Brave New World: Should we tread down the path to human germline editing?

5. In creating a regulatory framework for human germline editing, the following stakeholder views are important:

- (i) the views of scientists
- (ii) the views of policy-makers
- (iii) the views of philosophers
- (iv) the views of the public.

Choose the correct combination:

- a) *i* and *ii* are correct.
- b) *iv* is correct.
- c) *ii* and *iii* are correct.
- d) All of the above are correct.

6. Identify the correct international law which discusses modification of the human genome.

- a) the International Covenant for Civil and Political Rights
- b) the International Covenant for Socio-Economic and Cultural Rights
- c) the Oviedo Convention
- d) the Declaration of Human Rights.

A maximum of 3 CEUs will be awarded per correctly completed test.

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Enabling the use of health data for research: Developing a POPIA code of conduct for research in South Africa

7. What are the conditions that must be met for the lawful processing of personal information under the Protection of Personal Information (POPIA) Act?

- a) accountability, confidentiality, sharing of data, integrity, security
- b) accountability, processing limitation, purpose specification, further processing limitation, information quality, openness, security safeguards, data subject participation
- c) honesty, engagement, consent, participant protection
- d) data quality, data management, oversight, transparency, security.

8. What is the European Union data protection regulation?

- a) the General Data Protection Regulation
- b) the Declaration of Taipei on Ethical Considerations Regarding Health Databases and Biobanks
- c) the Convention for the protection of individuals with regard to the processing of personal data
- d) the International Ethical Guidelines for Health-related Research Involving Humans.

Physician-assisted suicide and euthanasia – who are the vulnerable?

9. In Chochinov's study of 213 terminally ill cancer patients with a life expectancy of <6 months, which of the following factors were associated with a loss of a sense of dignity?

- (i) significantly increased pain
- (ii) decreased quality of life
- (iii) difficulty with bowel functioning
- (iv) heightened dependency needs (bathing, dressing, incontinence)
- (v) loss of will to live
- (vi) increased desire for death
- (vii) depression
- (viii) hopelessness
- (ix) anxiety
- (x) patients' own perception of how they are seen by others.

Choose the correct combination:

- a) v, vi and vii are correct.
- b) i, iii and iv are correct.
- c) ii, viii and ix are correct.
- d) All of the above are correct.

10. True or false? Jones *et al.* found that in the USA, in states where physician-assisted suicide was legalised, there was a decrease in non-assisted suicides.

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