UNIVERSITY OF KWAZULU-NATAL

COLLEGE OF LAW AND MANAGEMENT STUDIES

SCHOOL OF LAW

# A virtual deliberative public engagement study on heritable genome editing among South Africans

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## COLLEGE OF LAW AND MANAGEMENT STUDIES

## DECLARATION 1 - PLAGIARISM

I, Elemme Wilfred, declare that

1. The research reported in this thesis, except where otherwise indicated, is my original research.
2. This thesis has not been submitted for any degree or examination at any other university.

......[redacted]....... ...............................

Date: 06/02/2025

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## ABSTRACT

Throughout human endeavour, balancing ethics and safety with progress has historically been challenging to achieve, and this remains true for heritable human genome editing (HHGE). While HHGE holds the potential to revolutionise medicine, it has also sparked a global debate regarding its ethical, social and regulatory implications. This study emphasises the importance of incorporating the South African perspective into this ongoing global debate by exploring the opinions of an informed South African public on the acceptable applications of HHGE for genetic health conditions, immunity and genetic enhancements through a deliberative public engagement study.

A qualitative thematic analysis following Braun and Clarke's six-phase method was conducted on participant responses, revealing a global theme: 'Balancing health benefits (including improvements to the quality of life) with unanticipated risks to individuals and society.' Seven principal themes emerged, reflecting key concerns: 'The potential benefits of HHGE', 'impact on natural immune responses', 'equitable access to HHGE for everyone', 'HHGE and discrimination in society', 'the right to autonomy', 'going against human nature' and 'ambiguity in reasons for opinion changes'. These findings highlight the necessity of public engagement in shaping HHGE policies, emphasising that legitimacy extends beyond legal validity to include moral authority and societal acceptance. Additionally, the results of the study may be advantageous to policymakers as evidence-based research for the future regulation of HHGE in South Africa, especially given its current legal position on HHGE.

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# *CHAPTER 1*

# *INTRODUCTION*

The world of medical science is dynamic and in constant progression, as it continues to extend the frontiers of knowledge;[1] however, such advancement becomes futile if left rejected by humanity. The discovery of CRISPR-Cas9 technology as a tool for the possible 'site-specific' alteration of human genetic material has reformed genomics, owing to its novelty in the field of biology.[2] Additionally, in conducting precise modifications to the human genome, it has the ability to combat genetic diseases while remaining inexpensive and efficient.[3] Despite its potential therapeutic benefits and popularity in the scientific domain, the scientific community concurs that CRISPR-Cas9, among other genetic engineering technologies, has not been proven to be adequately safe and effective for its potential use on human genetic material.[4] Beyond this concern, the technology has sparked extensive societal discourse regarding its ethical and legal implications for human clinical applications.[5]

Many authors, legislators and scientists agree that achieving broad societal consensus requires considering the views of the general public on a global scale,[6] particularly through deliberative public engagement (DPE). This approach would not only uphold democratic principles,[7] but also facilitate the development of a comprehensive regulatory framework – one that defines a clear path for the potential clinical applications of genome editing while incorporating diverse societal perspectives.[8] This is viewed as a form of '"democratization" of science'.[9] As Mill advocates,[10] diverse societal opinions enable the examination of conflicting

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[1] AS Litis, S Hoover & KRW Matthews 'Public and Stakeholder Engagement in Developing Human Heritable Genome Editing Policies: What Does it Mean and What Should it Mean?' (2021) 3 *Front. Polit. Sci.* 1–13 at 1.

[2] See JA Doudna & E Charpentier 'The new frontier of genome engineering with CRISPR-Cas9' (2014) 346 (6213) *Science* 1–9 at 1.

[3] Ibid.

[4] S van Baalen et al 'The DNA-Dialogue: A Broad Societal Dialogue About Human Germline Genome Editing in the Netherlands" (2021) 4(4) *The CRISPR Journal* 1 –21 at 3.

[5] Ibid at 3; International Academies of Science, Medicine and Engineering 'International summit on human genome editing' (2015) available at *https://www.nap.edu/catalog/21913/international-summit-on-human-gene-editing-a-global- discussion*, accessed on 20/05/2022.

[6] F Baylis 'Broad societal consensus' on human germline editing' (2016) 15(2) *Harv. Health Policy Rev.* 19–22 at 22.

[7] G Cavaliere, K Devolder & A Giubilini 'Regulating Genome Editing: For an Enlightened Democratic Governance' (2019) 28(1) *Camb Q Healthc Ethics* 76–88.

[8] Ibid at 77.

[9] See P Weingart, M Joubert & K Connoway 'Public engagement with science-Origins, motives and impact in academic literature and science policy' (2021) 16(7) *PLoS One* available at https:// doi.org/10.1371/journal.pone.0254201, accessed on 20/06/2022.

[10] JS Mill *On Liberty* London: Dent, (1979), as cited in Cavaliere op cit note 7 at 76.

ethical and practical issues, producing greater policy decisions.[11] However, the complexities involved in understanding public opinion and its potential shifts necessitate the use of advanced analytical techniques to extract meaningful insights and formulate relevant arguments.[12]

## I BACKGROUND

### *(a) CRISPR-Cas9 technology*

For centuries, the issue of sustaining and improving the quality of life has been integral to medical science, with this objective gradually attained through enduring technological innovation and medical advancements. The introduction of modern biotechnology has been significant in enhancing human welfare and meeting societal needs, enabling the development of new products through the use of technology and biological materials.[13] Following the discovery of the double-helical structure of DNA in 1953,[14] the era of modern biotechnology emerged, resulting in various scientific breakthroughs.[15] Accordingly, it was only a matter of time until the discovery of CRISPR-Cas9 technology for the possible modification of the human genome.

Since its public announcement in 2012, CRISPR-Cas9 technology, acclaimed as the 'genetic scissors', has garnered substantial attention for its capacity to effect targeted modifications to the human genome.[16] The technology comprises two components, namely, CRISPR,[17] and CRISPR-associated protein 9.[18] The first component, CRISPR, consists of two RNA[19] variants extracted from a bacterial pathogen known as streptococcus pyogenes.[20] These RNA strands merge to create a 'single guide RNA' (sgRNA) or what is commonly referred to

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[11] In Cavaliere op cit note 7 at 81.

[12] KC O'Doherty 'Synthesising the outputs of deliberation: Extracting meaningful results from a public forum' (2013) *9*(1) *Journal of Deliberative Democracy* 1–16 at 12, available at https://www.researchgate.net/publication/341076269_Synthesising_the_outputs_of_deliberation_Extracting_memeaningf_results_from_a_public_forum, accessed on 21/06/2022.

[13] AS Verma et al 'Biotechnology in the Realm of History' (2011) 3(3) *Journal of Pharmacy And Bioallied Sciences* 1–4 at 1 available at https://www.researchgate.net/publication/51687274 , accessed on 23/06/2022.

[14] This was discovered by Watson and Crick in 1953, see M Bansal 'DNA structure: Revisiting the Watson-Crick double helix' (2003) 85(11) *Current Science* 1555–1563 at 1556 available at https://www.researchgate.net/publication/237228525, accessed on 23/05/2022.

[15] K Nightingale 'DNA: a timeline of discoveries' (2020) available at *https://www.sciencefocus.com/the-human-body/dna-a-timeline-of-discoveries/*, accessed on 23/06/2022, see Doudna op cit note 2 at 1.

[16] H Ledford & E Callaway 'Pioneers of CRISPR gene editing win chemistry nobel' *Nature* 15 October 2020 346–347 at 346.

[17] An acronym for 'Clustered Regularly Interspaced Short Palindromic Repeats', see Nuffield Council on Bioethics 'Genome Editing: An Ethical Review' (2016) 1–128 at 9.

[18] Nuffield ibid at 9.

[19] An abbreviation for 'Ribonucleic acid', ibid at 5.

[20] Nuffield op cit note 17 at 8.

as guide RNA (gRNA).[21] The second component, CRISPR-associated protein 9, is the endonuclease or enzyme that aids in slicing through the targeted DNA region.[22] In a brief description of the genomic alteration process, the specific DNA target region is matched with a segment of the sgRNA, thus allowing for precision in alteration.[23] The other segment of sgRNA combines with the Cas9 enzyme and guides it to the targeted region to perform a 'double-strand' cut.[24] The DNA break or cut is then repaired through inbuilt cellular maintenance mechanisms that facilitate such alteration.[25] In this way, the desired genomic alteration may be achieved.[26]

CRISPR-Cas9 is deemed the leading technology in human genetic engineering.[27] Its prominent status owes to its potential to effectively alter genetic material by inserting, removing or replacing genes in somatic or germline cells.[28] In doing so, said technology may be utilised to treat or prevent hereditary diseases.[29] These diseases include, but are not confined to, haemophilia, cancer and cystic fibrosis.[30] Additionally, the manipulation of genetic material in affected individuals may also provide scientists and researchers with an improved understanding of the breadth and prospective concerns surrounding these diseases.[31] Conversely, alongside its potential therapeutic benefits, the technology may also be employed for non-therapeutic purposes, such as genetic enhancements.[32] However, as numerous studies have proven, the issue of said enhancements is often met with strong societal opposition.[33]

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[21] Ibid at 9.
[22] Ibid.
[23] Ibid.
[24] Ibid.
[25] Ibid.
[26] Ibid.
[27] A Blasimme 'Why include the public in genome editing governance deliberation?' (2019) 21(12) *AMA Journal of Ethics* 1065–1070 at 1065.
[28] Doudna op cit note 2; National Academies of Sciences, Engineering, and Medicine *Human Genome Editing: Science, Ethics, and Governance.* Washington, DC: The National Academies Press, (2017) 1–310 at 4.
[29] S Baliou et al 'CRISPR therapeutic tools for complex genetic disorders and cancer (Review)' (2018) 53 *International Journal of Oncology* 443–468 *at* 452.
[30] Ibid.
[31] K Ashok 'Gene Editing Technology' (2020) 1–4 available at https://www.researchgate.net/publication/347442835_GENE_EDITING_TECHNOLOGY, accessed on 25/05/2022.
[32] These include, the changing of one's skin tone, eye colour, hair colour, etc., see National Academies of Sciences, Engineering, and Medicine op cit note 28 at 137.
[33] To provide examples, see G Gaskell et al 'Public views on gene editing and its uses' (2017) 35(11) *Nat. Biotechnol* 1–11 at 5–6; see D Watanabe et al 'Increased awareness and decreased acceptance of genome-editing technology: The impact of the Chinese twin babies' (2020) 15(9) *PLoS One* 1–13 at 2.

### *(b) Heritable human genome editing: Somatic vs germline gene therapy*

Genetic modifications may be carried out in the somatic or germline cells of an organism. Somatic genome editing (SGE) involves the manipulation of genetic material in the non-reproductive (somatic) cells of a living individual to treat genetic diseases – changes that may not be inherited by future offspring.[34] Clinical trials using somatic editing to treat patients with advanced diseases have already received approval, despite the concerns raised.[35] In contrast, germline genome editing (GGE) involves inducing changes to the germline cells (reproductive cells or an embryo in its early stages of development) of an unborn child, where such changes may be *heritable*.[36] It is within this context that heritable human genome editing (HHGE) is introduced. HHGE arises when germline editing results in reproduction and the transmission of genetic changes to future generations.[37] As such, the *heritable* nature of these genetic modifications is a relevant concern and has provoked considerable societal contention.[38] Consequently, this dissertation focuses exclusively on HHGE. The notion of 'heritable changes' is novel and has since fostered significant societal outrage, particularly raising numerous legal and ethical questions.[39]

### *(c) Other methods of disease prevention*

It is worth noting that, along with its potential therapeutic benefits, HHGE does not appear to be the only available method for disease prevention in embryos.[40] This could also be achieved using donated gametes, not having a biological child or adoption; however, these methods do not permit a *genetic link* between both parents and are often less supported by society.[41] Additionally, preimplantation genetic diagnosis (PGD) offers an alternative, involving the screening of embryos for potential genetic conditions before implantation into the uterus during in vitro fertilisation (IVF).[42] Conversely, this method is frequently criticised due to its high costs and, more significantly, the ethical concerns surrounding the disposal of embryos.[43] As

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[34] National Academies of Sciences, Engineering, and Medicine op cit note 28 at 4, 5 & 83.

[35] Ibid.

[36] B Shozi 'An Afrocentric approach to CRISPR-Cas9: Analysing the use of genetic technologies in human reproduction through the lens of human rights and African values' (published doctoral thesis University of KwaZulu-Natal, 2021) at 2.

[37] F Baylis et al 'Human Germline and Heritable Genome Editing: The Global Policy Landscape' (2020) 3(5) *The CRISPR Journal*, 365–377 at 367.

[38] Shozi op cit note 36 at 3.

[39] National Academies of Sciences, Engineering, and Medicine op cit note 28 at 6.

[40] Ibid at 113.

[41] Ibid.

[42] Ibid; AM Ardekani 'Genetic technologies and ethics' (2009) 2 *J Med Ethics Hist Med* 1–4 at 2.

[43] National Academies of Sciences, Engineering, and Medicine op cit note 28 at 113.

such, HHGE presents a worthwhile area of exploration in the context of this dissertation as a means to alleviate these issues.

### *(d) HHGE: The South African legal framework*

The South African legal framework appears unclear regarding its position on HHGE, reflecting a sense of ambiguity.[44] This uncertainty may be justified, as there is no direct legislation regulating HHGE in South Africa, but rather an assumed position derived from legal policies that speak of similar activities.[45] The key legislation in this regard is the National Health Act (NHA).[46] Other pieces of legislation may be applicable, but are irrelevant to this study.[47] Moreover, guidance may be sought from ethical frameworks, such as the Health Professions Council of South Africa (HPCSA),[48] the Medical Research Council (MRC),[49] and the Department of Health (DoH)[50] guidelines. These are discussed below to determine the current legal position on HHGE in South Africa.

Section 57(1) of the NHA asserts that the manipulation of genetic material in human embryos, gametes, zygotes, or any activity involving the splitting of an embryo or nuclear transfer to produce a human being or 'reproductive cloning', is not permitted. However, it can be argued that section 57(1) does not prohibit 'therapeutic cloning', which is defined separately within the NHA,[51] and is sufficiently broad to include genomic therapy.[52] In the same breath, a literal interpretation of the aforementioned section could imply that not only cloning, but any form of genomic manipulation, is prohibited.[53] Conversely, the purpose of this dissertation is not to demystify the current South African legal position on HHGE,[54] but to contribute towards

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[44] BA Townsend & B Shozi 'Altering the Human Genome: Mapping the Genome Editing Regulatory System in South Africa' (2021) 24 *PER / PELJ* 1–28 at 5.

[45] Ibid.

[46] the National Health Act 61 of 2003.

[47] These include, the Medicines and Related Substances Control Act 101 of 1965; the Protection of Personal Information Act 4 of 2013; the Children's Act 38 of 2005; the Consumer Protection Act 68 of 2008 and the Patents Act 57 of 1978 as cited in Townsend & Shozi op cit note 44.

[48] Health Professions Council of South Africa 2008 Booklet 14: General Ethical Guidelines for Biotechnology Research in South Africa - Guidelines for Good Practice in the Health Care available at https://www.sada.co.za/media/documents/HPCSA_Booklet_14_Biotechnology_Research_in_SA.pdf, accessed on 30/05/2022.

[49] Medical Research Council 2001 Guidelines on Ethics for Medical Research: Reproductive Biology and Genetic Research (Book 2) available at http://www.mrc.ac.za/sites/default/files/attachments/2016-0629/ethicsbook2.pdf, accessed on 30/05/2022.

[50] Department of Health Ethics in Health Research (DoH guidelines), as cited in Townsend & Shozi op cit note 44 at 6.

[51] As per s57(1)(6)(b): therapeutic cloning refers to 'the manipulation of genetic material from either adult, zygotic or embryonic cells in order to alter, for therapeutic purposes, the function of cells or tissues.'

[52] See Townsend & Shozi op cit note 44 at 8.

[53] As suggested by Townsend & Shozi ibid at 8–9.

[54] In this case, see ibid.

the establishment of a clear and definite legal framework, based on scientific knowledge and most significantly – the views of lay society. However, it is readily apparent that the current legal status of clinical applications of HHGE in South Africa is complex and unclear.

Section 57(4) of the NHA establishes the '14-day rule' for HHGE research, prohibiting research on human embryos beyond 14 days of age. [55] If such research is deemed permissible, a written application must be submitted to the Minister for approval.[56] Any person who contravenes the provisions of section 57 commits an offence and may be fined or face imprisonment.[57] As such, the South African legal position on HHGE research reflects greater clarity than that concerning its potential clinical applications.

In the context of ethical considerations surrounding genome editing, the HPCSA issued a code of ethical practice for biotechnology research in South Africa in 2008.[58] As per paragraph 13.3, the code declares that 'no attempts should be made through the use of gene modification, to change human traits not associated with disease'.[59] Thus, genetic enhancements are ruled out. The MRC guidelines are analogous in this regard and echo a similar position in paragraph 3.2.2.1.[60] Furthermore, the HPCSA asserts that germline gene therapy research is 'not acceptable' due to the heritable nature of germline therapy.[61]

According to the MRC guidelines, paragraph 3.2.3 states that 'germline therapy should not be contemplated'.[62] Furthermore, 'gene modification of the human germline should not yet be attempted until such time that it is clearly sanctioned in South Africa',[63] in which the potential misuse of the technology is of primary concern.[64] Notwithstanding this stance, the MRC appears somewhat contradictory in paragraph 2.17, and pursues a relatively permissive slant.[65] Firstly, it acknowledges that early embryo research and manipulation could harvest great insight and may be resourceful in the medical community.[66] However, it stipulates that

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[55] See section 57(4)(a) of the NHA for the necessary requirements.

[56] Ibid.

[57] See section 57(5).

[58] Health Professions Council of South Africa op cit note 48.

[59] Ibid.

[60] It states that 'any attempt by gene modification to change human traits not associated with disease would be unacceptable' in MRC Book 2 para 3.2.2.1.

[61] Para 13.3.2 emphasises that 'Germline gene therapy involves the insertion of genes into eggs already fertilized or very early embryos. The inserted genes would be transferred to subsequent generations as it has the effect of modifying the human germline. Research relating to germline gene therapy is therefore not acceptable', in Health Professions Council of South Africa op cit note 48.

[62] Medical Research Council op cit note 49.

[63] Ibid para 3.2.3 and 3.2.3.1.

[64] Ibid para 3.2.3.

[65] D Thaldar et al 'Human germline editing: Legal-ethical guidelines for South Africa' (2020) 116(9/10) *S Afr J Sci* 1–7 at 2.

[66] Medical Research Council op cit note 49 para 2.17.

for the procedure to be considered ethical, embryos should not be created specifically to conduct genetic interventions.[67] Secondly, in referring to HHGE, it states that the embryo may only be conveyed to the human uterus if there exists reasonable certainty that the gene edit could be performed without posing any potential harm to the unborn child.[68] Based on these ethical guidelines, it can be inferred that future therapeutic applications of CRISPR-Cas9 technology are envisioned, as HHGE is not entirely outlawed.[69] However, as it stands, HHGE is not permitted in South Africa, following its legal and ethics framework.

### *(e) HHGE: The international legal policy perspective*

Considering the global framework, a recent study has revealed that out of 106 countries, 96 have relevant genomic editing policy instruments, with 78 countries possessing policies in direct relation to HHGE.[70] Significantly, 75 out of 78 countries (these include the UK, US, Germany, Russia, Japan, China, Canada, etc.) strictly prohibit HHGE, where only five prohibit it with exceptions (for example, Italy and Belgium).[71] The three remaining countries are categorised as 'indeterminate' (such as Ukraine).[72] It is interesting to note that 22 countries (amongst the 96 countries) have ratified the *Oviedo Convention*, under which HHGE is expressly banned.[73] Given the global data, it is evident that the issue of HHGE is not only contentious in South Africa but on a global scale.

### *(f) HHGE: A global moratorium and calls for DPE*

Notwithstanding the global climate, in 2018, the first case of HHGE was reported when Chinese biophysicist, He Jiankui, revealed that he had utilised CRISPR-Cas9 technology to edit the CCR5 gene, ultimately resulting in the birth of twin girls with potential HIV resistance.[74] In light of the gravity of his actions, a global moratorium was called for, requiring the suspension of all clinical applications of HHGE until a global consensus on its ethical and regulatory use could be reached.[75] In addition to this call, the International Commission on the

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[67] Ibid.
[68] Ibid.
[69] Townsend & Shozi op cit note 44 at 15.
[70] Baylis et al op cit note 37 at 369, 371.
[71] Ibid.
[72] Ibid.
[73] Ibid at 369, 366.
[74] VL Raposo 'The First Chinese Edited Babies: A Leap of Faith in Science' (2019) 23(3) *JBRA Assist Reprod* 197–199 at 197.
[75] ES Lander et al 'Adopt a moratorium on heritable genome editing' (2019) 567 *Nature* 165–168 available at https://doi.org/10.1038/d41586-019-00726-5, accessed on 02/06/2022, as cited in D Thaldar et al 'A virtual deliberative public engagement study on heritable genome editing among South Africans: Study protocol' (2021) 16(8) *PLoS ONE* 1–15 at 1.

Clinical Use of Human Germline Genome Editing expressed that, prior to national regulatory measures, 'extensive societal dialogue on HHGE' should be induced.[76] This could be attained through DPE measures, where public participation could minimise the burden on legislators in regulating scientific practices, and, as American philosopher John Dewey believed, 'lay deliberation and technical expertise can enrich each other.'[77] This owes to the absence of a value-based system in scientific reasoning, which is typically premised on factual enquiry.[78]

Public participation in scientific decisions through DPE could produce richer data by bridging facts and values.[79] It is relevant to note the shift in perspective associated with the 'deficit models of public understanding'[80] advanced by scientists, which suggest that public attitudes towards science stem from ignorance or the lack of scientific knowledge.[81] Conversely, the public is now regarded as fundamental to the regulation of scientific practices,[82] and may offer valuable insights for prospective policy development on HHGE. Thus, the question is no longer whether the public should be involved in such scientific policy decisions, or how to go about the process,[83] but how to elicit meaningful outcomes using DPE, that may be useful to policymakers. However, before addressing this question, it is important to understand the concept of DPE itself and the theories underpinning it.

### *(g) DPE: Deliberative democracy*

DPE, classified as the modern deliberative democracy,[84] may find its roots in the Athenian solution practised in classical Athens within the fifth century B.C, where an Athenian assembly was randomly selected to discuss matters of political interest.[85] It has been argued that such 'deliberative procedures and institutions meant to foster debate, exchange of points of view and ideas, and reasoned arguments' that were 'geared towards reaching, ultimately,

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[76] National Academy of Medicine, National Academy of Sciences & The Royal Society *Heritable Human Genome Editing* Washington, DC: The National Academies Press, (2020) 1–220, as cited in Thaldar et al ibid at 1.

[77] A Moore *Critical elitism: Deliberation, democracy, and the problem of expertise* Cambridge University Press, (2017) 1–211 at 28, as cited in EY Adashi et al 'Heritable human genome editing: The public engagement imperative' (2020) *3*(6) *The CRISPR journal* 434–439 at 435.

[78] T Dietz 'Bringing values and deliberation to science communication' (2013) 110 *Proceedings of the National Academy of Sciences* 14081–14087 at 14081.

[79] Ibid.

[80] O'Doherty op cit note 12 at 126–127.

[81] Ibid.

[82] Ibid at 127.

[83] Adashi et al op cit note 77. For study protocol on how DPE can be executed, see Thaldar et al op cit note 75.

[84] Thaldar et al op cit note 75 at 2.

[85] JS Fishkin 'Deliberative Democracy' in JS Fishkin *Democracy when the people are thinking*: *revitalizing our politics through public deliberation* Oxford University Press, (2018) 1–251 at 26.

consensus.'[86] Furthermore, that this system was 'the key presupposition for the legitimacy of the democratic system.'[87] However, despite the presence of deliberative ideologies, it is unclear as to whether the Athenians had centralised the element of 'deliberation' in decision-making, as is evident in modern versions of the concept, given that deliberation was incidental to the voting procedure.[88] As such, it remains doubtful that the Athenians had embraced the true spirit of DPE.

In broad terms, 'public engagement' refers to the numerous means of exchanging views, opinions or information between decision-makers and the public.[89] The public may contribute to decisions involving policy formulation or agenda-setting through deliberative institutions, such as facilitated small-group discussions, citizens' juries, etc.[90] Deliberation, when viewed independently, incorporates the 'discussion' component, whereby, through dialogic procedures (virtual or face-to face), the public are given time to reflect on relevant issues and discuss possible solutions based on acquired or original knowledge.[91] In this way, the process of DPE differs from traditional means of public engagement, namely opinion polls, as the public are not merely indicating their preferences but are doing so after careful consideration of new information, ideas and the arguments advanced by other participants.[92] Thus, *informed opinion* is the ultimate result.[93] The modern model of *deliberative democracy* put forward by John Rawls and Jürgen Habermas accentuates the aspect of 'deliberation' in democratic practices to create 'just normative social forms.'[94] This encourages a form of active citizenry, where public participation in decisions concerning political policy not only revives democratic principles such as inclusiveness and transparency, but also safeguards against authoritarianism[95]– a system of restricted political pluralism.[96]

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[86] M Canevaro et al *Ancient Greek History and Contemporary Social Science* (ed) Edinburgh: Edinburgh University Press, (2018) 1–213 at 125, as cited in D Cammack 'Deliberation and discussion in classical Athens' (2020) *Journal of Political Philosophy* 1–32 at 1–2.

[87] Ibid.

[88] Cammack op cit note 86.

[89] N Cass 'Participatory-Deliberative Engagement: a literature review' (2006) at 4.

[90] D Warburton et al *Deliberative public engagement: nine principles* London: National Consumers Council, (2008) 1–16 at 5.

[91] Ibid at 2.

[92] Ibid, also see D Thaldar et al 'A deliberative public engagement study on heritable human genome editing among South Africans: Study results' (2022) 17(11) *PLoS ONE* 1–19 at 3.

[93] O'Doherty op cit note 12 at 136.

[94] Thaldar et al op cit note 75 at 2.

[95] Organisation for Economic Co-operation and Development 'Innovative citizen participation and new democratic institutions: Catching the deliberative wave' (2020) 1–44 at 6 available at https://www.oecd.org/gov/open-government/innovative-citizen-participation-new-democratic-institutions-catching-the-deliberative-wave-highlights.pdf, accessed on 10/06/2022.

[96] O Schlumberger 'Authoritarian regimes' (2017) *Oxford Handbooks Online* 1–36 at 2.

The notion of *public reason* advocated by Rawls is grounded in the principle of 'public justification of political power'.[97] The pluralistic nature of society dictates that, despite profound differences and imbalances in reasonable and comprehensive societal doctrines, owing to a 'culture of free institutions',[98] there should be some common ground through which laws, political systems and the behaviour of political actors are justified.[99] Therefore, citizens should endorse only those political systems or fundamental laws which, in their view, incorporate 'political values' that may reasonably be approved by others and,[100] in turn, justifiable to them.[101] Furthermore, considering the inconsistencies inherent in differing societal principles, values and beliefs, and issues of compatibility, it is imperative that citizens take into account the 'reasons they may reasonably give one another when fundamental political questions are at stake.'[102]

The works of Habermas provide a standards-based argument for deliberation, in which his moral theory – known as 'discourse ethics' – offers a dialogic framework for resolving ethical conundrums through rational reasoning.[103] In his discourse principle, drawing upon the writings of German philosopher Immanuel Kant and providing a revised version of Kant's idea of *universalisation*,[104] he elucidates that 'only those norms can claim to be valid that meet (or could meet) with the approval of all affected in their capacity as participants in a *practical* discourse'.[105] Thus, he believes such validation is subject to 'collective efforts' in decision-making,[106] and is further underpinned by fair democratic procedures and 'informed decision-making'.[107] In addition, his theory of communicative action sought to reform traditional methods of social action, such as 'strategic action',[108] by emphasising that political actors

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[97] J Quong 'On the idea of Public Reason' in W Blackwell *A Companion to Rawls* John Wiley & Sons, Inc, (2013) at 1.

[98] J Rawls 'The Idea of Public Reason Revisited' (1997) 64(3) *The University of Chicago Law Review* 765–807 at 766.

[99] Quong op cit note 97 at 1.

[100] Ibid.

[101] Ibid.

[102] Rawls op cit note 98 at 766.

[103] G Bhattacharjee 'Habermasian discourse theory of morality: A critique' (2021) 9(10) *IJAR* 850–856 at 851.

[104] MJ Ford 'Jurgen Habermas: Discourse Ethics and the Development of a Contemporary Christian Ethic' (published Master's thesis, McMaster University, 2003) at 96.

[105] J Habermas 'Discourse Ethics: Notes on a Program of Philosophical Justification', (1990), as cited in Kettner, M 'Discourse ethics Apel, Habermas, and beyond' in C Rehmann-Sutter et al (eds) *Bioethics in Cultural Contexts: Reflections on Methods and Finitude* Springer, (2006) 299–318.

[106] Ford op cit note 104 at 64.

[107] Thaldar et al op cit note 75 at 2.

[108] K Sharlamanov & J Aleksandar 'Analysis of Theory of Communicative Action' (2020) 8 *Journal of International Scientific Publications* 365–371 at 366.

should encourage mutual understanding and consensus in deliberation, striving to understand one another instead of trying to be influential.[109]

As derived from the merging of Rawls's concept of 'public reason' and Habermas's 'discourse ethics', public deliberation broadens democratic procedures by generating various options for consideration.[110] It enables the creation of an informed public by increasing societal awareness and understanding of novel technologies, as well as the difficulties inherent in regulating said technologies.[111] In doing so, it allows one to gauge public knowledge of these technologies and ultimately speak to their concerns.[112] Accordingly, it can be said that such deliberative procedures may be instrumental in promoting greater efforts to achieve participatory democracy, and could be advantageous within a constitutional dispensation such as South Africa's.

### *(h) Public participatory model in South Africa*

In South Africa, public involvement in policy questions is integral to democratic practice and the sustainability of its constitutional democracy.[113] This ensures the decentralisation of governmental power,[114] and allows for transparency and accountability in conducting governmental affairs.[115] Additionally, in light of South Africa's fragmented past, marked by racial segregation and the exclusion of a portion of the citizenry from political decision-making,[116] public involvement now helps ensure that all citizens are included in these processes.[117]

Constitutionally entrenched mechanisms facilitate public participation in political decisions,[118] namely *representative* and *participatory* democracy. In brief terms, representative democracy presents a system in which public views are voiced through elected representatives.[119] This may be problematic, especially in the case of nepotism, greed and self-

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[109] Cass op cit note 89 at 8.

[110] Thaldar et al op cit note 75 at 2.

[111] Ibid.

[112] Ibid.

[113] S Stuurman 'Public participation, matters of democracy and service delivery: a perspective from below' *Journal of Public Administration* (2019) 54(2) 325–333 at 267–268.

[114] Ibid at 326.

[115] Ibid at 331.

[116] Ibid at 309.

[117] Ibid at 325.

[118] Constitution of the Republic of South Africa, 1996. This is discussed in more detail in Chapter 2.

[119] See LJ Modise 'The notion of participatory democracy in relation to local ward committees: The distribution of power' (2017) 51(1) *In die Skriflig* 1–8 at 2.

motivated interests, which can lead to failed attempts at effective public engagement.[120] Participatory democracy, on the other hand, prompts a more direct approach, allowing citizens to address their concerns in their own capacities and actively participate in policy questions.[121] Despite ambitious attempts, current measures to achieve participatory democracy in South Africa appear unviable, given the challenges of implementation[122] and the potential exclusion of citizens at the grassroots level from decision-making.[123] It is beyond the scope of this dissertation to discuss these challenges; however, it is vital to highlight one significant challenge, namely, mistrust of the public in governmental affairs.[124] Thus, DPE, as a novel tool for public participation, would not only supplement current efforts at participatory democracy but also claims to secure public trust in emerging technologies, given its normative foundations (as discussed above).[125] This, in turn, may lead to higher-quality policy decisions, mainly attributable to informed public input.[126] However, this outcome would depend significantly on how the deliberation data is *analysed*.

### *(i) DPE outcomes: Data analysis*

The employment of deliberative measures in public engagement appears promising but may only be fruitful insofar as they are able to yield meaningful or intended results.[127] Otherwise, they risk being perceived similarly to other non-deliberative forms of public engagement. For the result to be classified as meaningful or intended, it is important to first define the scope of the deliberation outcome or the intended result.[128] Significantly, there are no guidelines for this purpose, i.e., on how the product of deliberation should be defined or how deliberation data should be synthesised to inform policy development.[129] Furthermore, if one had to analyse the goals of deliberation (for example, *informed citizenry* or *collaborative decision-making*), these may only be useful for stipulating the quality of the deliberation outcome and the process by

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[120] Ibid at 1.

[121] A Kabingesi 'An assessment of public participation in the law-making and other activities of the Parliament of the Republic of South Africa' (published Master's thesis, Stellenbosch University, 2021) at 17.

[122] Public Service Commission 'Report on the Assessment of Public Participation Practices in the Public Service' Pretoria: Government Printers (2008) at 11 available at https://www.gov.za/sites/default/files/gcis_document/201409/pscreportassessdec20080.pdf, accessed on 13/06/2022.

[123] Modise op cit note 119 at 7.

[124] Public Service Commission op cit note 122.

[125] This is particularly one of the many advantages of employing a DPE technique, see BA Townsend 'Human genome editing: How to prevent rogue actors' (2020) 21(1) *BMC Medical Ethics* 1–10 at 5,7.

[126] Ibid at 5.

[127] O'Doherty op cit note 12 at 3.

[128] Ibid.

[129] Ibid.

which this quality is achieved.[130] O'Doherty postulates that the concepts of meta consensus[131] and intersubjective rationality,[132] advanced by Niemeyer and Dryzek as the 'ideal outcomes of deliberation', should be observed as criteria for assessing the quality of the deliberation outcome against 'normative theoretical models of deliberative democracy'.[133] However, this does not prescribe how the deliberation data should be synthesised and subsequently reported for policy formulation,[134] primarily regarding the production of the 'analytical output' of the deliberative study.

The results of the deliberative study may be categorised as *deliberative* or *analytical*.[135] The *deliberative output* is relatively straightforward, referring to the collective position taken by the deliberants in the study, based on aggregated preferences.[136] Conversely, the quantitative or qualitative data may be further analysed using social scientific methods to extract valuable insights.[137] This is known as the 'analytical output', where additional analyses are conducted beyond the deliberative output to reveal otherwise concealed information.[138] Accordingly, it is this aspect of the analysis which is particularly central to this dissertation, as it may prove beneficial to policymakers.

### *(j) Deliberative public engagement study on HHGE in South Africa*

South African academics have exhibited significant initiative in conducting the first DPE study on HHGE in Africa (in virtual form).[139] This marks a critical milestone in South African history, in attempts to pave the way for potential HHGE legislation. Accordingly, it may be described as a 'landmark study'. A summarised version of the study has been provided below.

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[130] Ibid at 2, 3.

[131] This is defined as 'agreement about the nature of the issue at hand, not necessarily on the actual outcome', see S Niemeyer & JS Dryzek 'The Ends of Deliberation: Metaconsensus and Intersubjective Rationality as Deliberative Ideals' (2007) 13(4) *Swiss Political Science Review* 497–526 at 500, as cited in O'Doherty op cit note 11 at 3.

[132] This occurs 'when individuals who agree on preferences also concur on the relevant reasons, and vice versa for disagreement', see Niemeyer ibid.

[133] O'Doherty op cit note 12 at 3.

[134] Ibid.

[135] Ibid at 7.

[136] Ibid.

[137] Ibid.

[138] Ibid at 7, 12.

[139] Thaldar et al op cit note 75.

### *(i) Method*[140]

In accordance with deliberative standards of public engagement,[141] 13 policy proposals were presented to a diverse group of 30 South African participants, who were selected upon passing an entrance exam (which was sine qua non for participation).[142] The deliberation was conducted in three phases, namely, 'pre-deliberation, at the deliberation, and post-deliberation' for data collection.[143] Thus, participants were presented with the policy questions a week prior to the deliberation (pre-deliberation (T1)), during the deliberation (T2), and a week after the deliberation (post-deliberation (T3)).[144] The deliberation itself took place over the course of three consecutive evenings, with three separate topics for discussion.[145] These were expressed as: 'Prevention of genetic health conditions', 'editing for immunity', and 'editing for enhancement'.[146]

During each evening, the participants were welcomed by the plenary facilitator, who presented the policy proposals in accordance with the evening's theme.[147] The participants were then divided, at random, into six breakaway groups, each comprising five members and a group facilitator.[148] After 25 minutes of deliberation, participants returned to a plenary discussion, during which a randomly selected group member reported on the findings of the group.[149] This was followed by a second breakaway session of 35 minutes, after which the plenary reconvened and repeated the same protocol as the first.[150] Lastly, the participants were asked to cast their votes using the Zoom polling feature, and the evening concluded with the plenary facilitator revealing the voting results.[151] All plenary and breakaway discussions were recorded and subsequently transcribed (verbatim).[152] It is important to note that, although reasonable efforts were made to achieve consensus during the study, they were not implemented with coercion.[153]

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[140] This is merely a summarised version of the study method, see Thaldar et al for the full study method and process, op cit note 75.
[141] Thaldar et al op cit note 92 at 1.
[142] The candidates had unlimited attempts at taking the exam, however selection was based on ten or lessor successful attempts, see Thaldar et al op cit note 75 at 6.
[143] Thaldar et al op cit note 92 at 10.
[144] Ibid at 9.
[145] Ibid at 9.
[146] Ibid.
[147] Ibid.
[148] Ibid.
[149] Ibid at 10.
[150] Ibid.
[151] Ibid.
[152] Ibid at 9.
[153] Ibid at 10.

*(ii) Policy Proposals*

The following policy proposals were presented to the participants:

Topic 1: 'Provided that it is safe and effective, our country's laws should allow parents to choose to use genome editing before a child's birth to–

P1. prevent the child from being born with a serious heritable disease like sickle cell anaemia, muscular dystrophy, or Alzheimer's.
P2. prevent the child from being born with a less serious heritable disease like asthma or eczema.
P3. prevent the child from being born with a disability like deafness or blindness.
P4. prevent the child from being born with albinism.
P5. prevent the child from being born with Down's syndrome.'[154]

Topic 2: 'Provided that it is safe and effective, our country's laws should allow parents to choose to use genome editing before a child's birth to–

P6. make the child immune to contracting a serious disease like TB during the child's life.
P7. make the child immune to contracting a serious but mostly preventable disease like HIV/ Aids during the child's life.
P8. make the child immune to contracting Covid-19 during the child's life.
P9. make the child immune to contracting an illness like the flu or a common cold during the child's life.'[155]

Topic 3: 'Provided that it is safe and effective, our country's laws should allow parents to choose to use genome editing before a child's birth to–

P10. influence talents such as how intelligent or athletic the child will be.
P11. influence personality traits, such as how aggressive or cooperative the child will be.
P12. influence the sexual orientation of the child.
P13. determine aesthetic characteristics, such as the child's skin tone (to be lighter or darker) or the child's eye colour.'[156]

As such, only three possible responses to the policy proposals were acceptable, of course, with reasoning:[157]

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[154] Ibid at 8.
[155] Ibid.
[156] Ibid at 9.
[157] Ibid.

- Yes, always.
- Yes, subject to certain conditions.
- No, never.

In the study, intelligence and athleticism were combined into one policy proposal for the purposes of time.[158] This was also the case with aggression and cooperativeness.[159] Furthermore, TB and HIV/AIDS, although previously combined, were separated into two policy proposals for the reasons advanced in the study.[160] Accordingly, 13 policy proposals were presented to the study participants, as provided above.

*(iii) Results*

The voting results divulged significant support for HHGE in the case of serious heritable diseases.[161] However, for less serious heritable diseases, the majority of participants indicated 'yes, subject to certain conditions', precisely with regard to albinism.[162] TB and HIV/AIDS received strong support, with the majority of participants in favour of gene editing for immunity, though less support was expressed for COVID-19.[163] Lastly, HHGE for genetic enhancements was largely rejected by most participants.[164] Accordingly, the results reveal a 'health-focused risk-benefit paradigm', wherein potential therapeutic benefits are weighed against possible risks to health.[165]

*(iv) Changes in opinion*

In addition to the aforementioned data, the results also disclosed changes in opinion from T1 to T3, which are discussed briefly below.

*Theme 1: Prevention of genetic health conditions*

In terms of P1 (serious heritable diseases), there was a significant increase in support for the unconditional use of HHGE, rising from 65% to 93%, and in the case of P5 (Down's syndrome), from 45% to 79%.[166] However, the change in P2 (less serious heritable conditions) was relatively minor, increasing only from 24% to 38%.[167] Similarly, in the case of P3

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[158] Ibid.
[159] Ibid.
[160] Ibid at 9.
[161] Ibid at 10–11.
[162] Ibid.
[163] Ibid.
[164] Ibid.
[165] Ibid at 12, 13.
[166] Ibid at 12.
[167] Ibid.

(disability like deafness or blindness), from 66% to 79%, and P4 (albinism), from 21% to 28%.[168] P2 (less serious heritable conditions) and P4 (albinism) remained subject to conditional use by the majority of participants; thus, the changes in opinion did not alter this status.[169] These conditions are analysed and discussed in greater depth in Chapter 4.

*Theme 2: Editing for immunity*

P6 (TB) received a significant increase, from 38% to 59%, for the unconditional use of HHGE.[170] For P7 (HIV/AIDS), there was a minor increase from 41% to 59%.[171] This contrasted with P8 (COVID-19), which experienced a rise in 'opposition' towards the use of HHGE, from 24% to 41%, although a small majority (59%) still supported either its unconditional or conditional usage.[172] Any form of support for HHGE concluded with P9 (flu or a common cold), which saw a slight increase in support from 14% to 24%.[173] However, a small majority of participants remained opposed to the use of HHGE for P9, with opposition increasing from 48% to 52% between T1 and T3.[174]

*Theme 3: Editing for enhancement*

It is notable that despite vast opposition to the clinical use of HHGE for genetic enhancements (aesthetic characteristics and personality traits) across all policy proposals (P10-P13), there were no changes in opinion from T1 to T3.[175] As such, this position remained constant. However, considering the 'health-focused risk-benefit paradigm' raised by Thaldar et al,[176] this outcome may be attributable to the non-therapeutic nature of genetic enhancements.

Accordingly, of particular interest to this dissertation are not only the reasons for the opinions advanced by the participants within the study, but also the reasons for changes in those opinions.

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[168] Ibid.
[169] Ibid.
[170] Ibid at 13.
[171] Ibid.
[172] Ibid.
[173] Ibid.
[174] Ibid.
[175] Ibid.
[176] Ibid.

## II STATEMENT OF PURPOSE

Following the observations of a deliberative public engagement study on HHGE conducted in South Africa,[177] South African academics have decided that in order to accurately capture the informed South African perspective on HHGE, and to attain valuable insight for prospective policy formulation, a further analysis of the collected data becomes pivotal.

In examining the results of said study, this dissertation seeks to answer the following key research question: *What is the informed South African perspective on heritable human genome editing?*

In order to garner the South African perspective, the following sub-research questions (SRQs) need to be investigated:

- SRQ 1: What is the informed South African public perspective on the use of HHGE to prevent genetic health conditions?
- SRQ 2: What is the informed South African public perspective on the use of HHGE to enhance immunity against infectious diseases?
- SRQ 3: What is the informed South African public perspective on the use of HHGE to edit for genetic enhancements?

In addition to this inquiry, the study aimed to understand:

  - SRQ 4: Why did the informed South African public change their opinions during the study?

## III RATIONALE

The South African legal position on HHGE appears indefinite, as alluded to earlier.[178] Furthermore, the prohibition of HHGE applications by the relevant ethical guidelines (as previously expressed),[179] does not alleviate this dilemma, but creates further inconsistencies. As such, the aforementioned study has the potential to ameliorate this position by not merely demonstrating the South African collective stance on HHGE, but also by providing insight into the thought processes of an informed South African public regarding perceptions of HHGE.

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[177] Thaldar et al op cit note 75.

[178] Townsend & Shozi op cit note 44.

[179] Health Professions Council of South Africa op cit note 46; Medical Research Council op cit note 48.

This may prove advantageous for prospective HHGE policy formulation.[180] However, this unique form of data can only be attained through additional analytical measures, whereby the deliberation data is further analysed to produce an analytical output.[181] Hence, the significance of this dissertation.

Achieving complete consensus in a DPE setting is desirable; however, it is often impossible in the context of complex scientific decisions, such as the regulation of HHGE.[182] Nevertheless, this does not diminish the potential role of DPE in informing policy formulation, as it allows legislatures to discover their limitations when regulating HHGE, taking into account societal ethical concerns and the opinions raised during the deliberations.[183]

The results of the DPE study in South Africa, as outlined earlier, constitute the 'deliberative output', which reflects the collective position of the participants on the clinical uses of HHGE.[184]

To act on this data alone would be denying policymakers access to a richer source of insight, which would otherwise be attained through further inquiry into the underlying reasons for the opinions expressed or changes in opinion.[185] It is this particular component (changes in opinion), amongst others, that makes the process of DPE distinguishable from other methods of public engagement, as it is not only the ability to change minds but also the underlying justifications for these opinion changes that present a rare data source to policymakers.[186] This was particularly emphasised in a deliberative study on policy design in Australia, where significant shifts in opinion occurred in response to differing viewpoints and new perspectives.[187] It was found that analysing the justifications behind opinion changes or the fostering of agreement provided unique data to policymakers, offering deeper insight into what the public viewed as paramount.[188] Additionally, it may prove resourceful in envisaging the success or failure of future policies.[189] As such, the role of post-deliberation data analyses becomes crucial in obtaining this valuable insight and in averting potential policy failures.[190]

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[180] O'Doherty op cit note 12 at 5.

[181] Ibid at 7–8.

[182] Thaldar et al op cit note 92 at 2.

[183] Ibid.

[184] O'Doherty op cit note 12 at 7.

[185] A Stark, NK Thompson & G Marston 'Public deliberation and policy design' (2021) 4(4) *Policy Design & Practice* 452–464 at 459.

[186] Ibid at 454.

[187] Ibid at 457.

[188] Ibid at 459, 462.

[189] Ibid at 462.

[190] Ibid.

In conducting further analyses of the deliberation data, policymakers may be informed as to how the informed South African public allocates weight to certain arguments, or the underlying reasons that were substantial in opinion changes, thus aiding in the future regulation of HHGE.[191] It would allow policymakers to immerse in, and act upon, what the informed South African public deems significant or fearful in the process of HHGE itself, precisely when creating policies.[192] The public would then be supplementing policy decisions rather than making them, which is often feared by policymakers in deliberative procedures.[193] Ultimately, this would ensure greater democratic legitimacy of future HHGE policies through the establishment of 'public trust in, and acceptance of, new technologies'.[194]

Accordingly, it is this insight into the cognitive processes of the informed South African public which would be most fruitful to policymakers, and such insight may only be obtained through additional, post-deliberation analyses of the deliberation data.

## IV CONCEPTUAL FRAMEWORK

This dissertation will explore a critical realist framework for qualitative data analysis when conducting the relevant analyses of the transcripts.

## V LITERATURE REVIEW

On a global scale, the incorporation of DPE techniques in modern political systems has received overwhelming support, where there is vast literature on how this process ought to be executed, its potential benefits, and on how these practices have already been implemented across multiple disciplines; yet, lacking in the literature are suitable, deliberative-specific analysis methodologies or guidelines for the synthesis of collected data.[195] O'Doherty suggests that this may be due to the process being perceived as 'obvious'.[196] However, this is indeed a misconception, as identifying the most appropriate method to secure a fruitful outcome for policymakers can be a challenging endeavour. Accordingly, the following section entails a discussion of the relevant literature pertaining to: (a) current methodologies for the analysis of deliberation data; (b) changes in public opinion; and (c) the arguments for and against HHGE.

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[191] Ibid at 459; also see O'Doherty op cit note 12 at 5.

[192] Thaldar et al op cit note 92.

[193] Stark, Thompson & Marston op cit note 185 at 453.

[194] Townsend op cit note 125 at 5.

[195] See O'Doherty op cit note 11 at 3.

[196] Ibid at 4.

### *(a) Current methodologies for the analysis of deliberation data*

An examination of several DPE studies across multiple disciplines reveal a customary approach in the analysis of deliberation data, known as *thematic content analysis,* which is often coupled with *inductive* or *deductive* coding.[197] To provide examples, four deliberative studies in Canada have used inductive thematic content analysis to gather analytical outputs.[198] In a US study on biobank governance, the transcripts and notes were analysed using content analysis to extract the recommendations voted on by deliberants, which were then thematically analysed.[199] A similar approach was taken in a deliberative study on assisted reproductive technologies and budgetary resource allocation in Australia, where thematic analysis was used to examine deliberative forums and transcripts.[200] Significantly, these analysis methodologies were also employed in the South African landscape;[201] Tugendhaft et al report on the use of a context-specific public engagement tool (CHAT)[202] to determine a priority setting for health conditions, in which the collected data was analysed using thematic content analysis.[203] This was also apparent in another South African deliberative study, where a thematic content analysis was applied to transcriptions, using inductive and deductive coding.[204] These methods have also been used in isolation. For example, in West Africa, data from a road safety deliberative workshop was analysed solely using thematic analysis.[205]

These methods have been subject to criticism in the DPE domain, despite frequent usage in deliberation data analysis. O'Doherty argues that conventional methods of qualitative

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[197] See G Bartlett et al 'Deliberative stakeholder consultations: creating insights into effective practice-change in family medicine' (2018) 35(6) *Family Practice* 749–752 at 751; see S Puzhko, J Gagnon & J Simard 'Health professionals' perspectives on breast cancer risk stratification: understanding evaluation of risk versus screening for disease' (2019) 40(2) *Public Health Reviews* 1–19 at 6; see C Longo et al Addressing ethical challenges at the intersection of pharmacogenomics and primary care using deliberative consultations (2016) 17(16) *Pharmacogenomics* 1795–1805; see C Longo, V Rahimzadeh & G Bartlett 'Communication of Pharmacogenomic test results and treatment plans in paediatric oncology: deliberative stakeholder consultations with parents' (2021) 20 *BMC Palliative Care* 1–12 at 5.

[198] Ibid.

[199] SM Dry et al 'Community recommendations on biobank governance: Results from a deliberative community engagement in California' (2017) 12(2) *PloS one* 1–14 at 6.

[200] K Hodgetts et al 'Disinvestment policy and the public funding of assisted reproductive technologies: outcomes of deliberative engagements with three key stakeholder groups' (2014) 14(1) *BMC Health Services Research* 1–13.

[201] A Tugendhaft et al 'CHAT SA: Modification of a Public Engagement Tool for Priority Setting for a South African Rural Context' (2022) 11(2) *Int J Health Policy Manag* 197–209 at 198.

[202] An acronym for 'Choosing All Together', see Tugendhaft ibid at 198.

[203] Tugendhaft et al op cit note 201 at 201.

[204] CB Krubiner et al 'The Value of Explicit, Deliberative, and Context-Specified Ethics Analysis for Health Technology Assessment: Evidence from a Novel Approach Piloted in South Africa' (2023) 34 *Value in Health Regional Issues* 23–30, at 24.

[205] EMC Sween-Cadieux, C Dagenais & Valéry Ridde 'A deliberative dialogue as a knowledge translation strategy on road traffic injuries in Burkina Faso: a mixed-method evaluation' (2018) 16(1) *Health research policy and systems* 1-13, at 5.

data analysis, such as thematic or content analysis, find more suitable application in data captured during interviews or focus groups and not in the DPE context.[206] He reasons that said methods are insufficient in drawing distinctions between arguments made during the different stages of deliberation (prior to, during and at the end of deliberations); as such, they're unable to accommodate opinion changes but could be advantageous in other aspects.[207] This view was also supported by Bentley et al[208] and Gagnon et al, where it was added by Gagnon that these methods alone cannot be used for the synthesis of deliberation data, as they do not indicate 'the extent to which propositions represent the collective position.'[209]

It is further suggested that such methods may still be rewarding if integrated with *ethnographic participant observation* for the quality assessment of the deliberations.[210] Thus, *thematic analysis* would be useful in describing the deliberants' perceptions of the issues at hand, identifying when agreement or consensus was reached, whilst *content analysis* would be more effective in illuminating the argumentative framework behind the arguments made by the deliberants.[211] In addition, *ethnographic participant observation* would be supplemental in assessing the quality of the deliberations, where the participants are observed during the study for contextual factors or precisely, their cultural background.[212] However, this method would be impractical in the context of this study, as the implementation of *ethnographic participant observation* is required during the process of deliberative discussions;[213] furthermore, assessing the quality of the deliberative study is beyond the scope of this dissertation.

Notwithstanding their limitations, thematic and content analysis have been applied in a multitude of DPE studies (as expressed above) and would still be beneficial in analysing deliberation data, as has been conceded to by the critics themselves.[214] It is also important to emphasise that the aforementioned deliberative study on policy analysis in Australia, which reported on the value in public opinion changes, had merely performed a 'light content analysis' on the relevant transcripts.[215] Moreover, the inability of these methods to account for

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[206] O'Doherty op cit note 12 at 1, 5, 6, 7.

[207] Ibid at 7.

[208] C Bentley et al 'Trade-offs, fairness, and funding for cancer drugs: key findings from a deliberative public engagement event in British Columbia, Canada' (2018) 18 *BMC Health Services Research* 1–13 at 4.

[209] J Gagnon et al 'Understanding how professionals cultures impact implementation of a pediatric oncology genomic test: using ethnographic participant observation in deliberative stakeholder consultations' (2019) 33(7/8) *Journal of Health Organization and Management* 919–928 at 922.

[210] Ibid.

[211] Ibid at 923.

[212] Ibid at 923, 926.

[213] Ibid at 923.

[214] O'Doherty op cit note 12; Gagnon op cit note 209.

[215] Stark, Thompson & Marston op cit note 185 at 457.

changes in opinion does not function at a loss, as no such methodology currently exists to perform this function. Thus, it would have to be conducted manually by analysts. However, the tools present in thematic and content analysis may still aid the process of analysis. These methodologies are explored in more detail below.

### *(i) Thematic analysis*

Thematic analysis, often adopted as a conventional technique in qualitative data analyses, finds its roots in the field of psychology; however, used across multiple disciplines.[216] It is deemed the bedrock of other social scientific analysis methodologies, yet despite broad application, it appears ill-defined – there is no unanimity regarding its precise definition or methodical process.[217] Moreover, it is not conceived within, and does not conform to a particular theoretical framework or epistemological tradition; therefore, depending on the nature of the study, it may be expressed within realist or constructionist notions (this will be discussed later on).[218] As such, thematic analysis is perceived by some scholars as an accessory in data analysis, rather than an independent analytical method.[219] Braun and Clarke disagree, stating that it should be viewed distinctly, as such theoretical freedom enables versatility in application, and it may be useful in its ability to provide a 'rich and detailed, yet complex account of data.'[220] In addition, they argue that most analytical methods, such as content and discourse analysis, are primarily thematic in nature, yet titled differently. [221]

In broad terms, thematic analysis allows for the identification of themes or patterns within the dataset, which are subsequently analysed and reported.[222] These themes may be generated through *inductive* or *deductive* coding, as discussed below.[223]

An *inductive coding* procedure involves a bottom-up approach, in which themes are identified as existing within the dataset, and not in accordance with a pre-existing coding structure or the relevant research questions.[224] Therefore, such themes are closely related to the dataset and may have minor relations with the actual research questions.[225] However, the idea

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[216] V Braun & V Clarke 'Using thematic analysis in psychology. Qualitative Research in Psychology' (2006) 3(2) *Qualitative research in psychology* 77–101 at 4 available at http://eprints.uwe.ac.uk/11735, accessed on 17/08/2022.

[217] Ibid at 4, 6.

[218] Ibid at 4, 5.

[219] Ibid at 4.

[220] Ibid at 5.

[221] See for relevant example, ibid at 4.

[222] Ibid at 6.

[223] Braun & Clarke op cit note 216 at 12.

[224] Ibid.

[225] Ibid.

of pre-existent themes within the dataset has been criticised, considering that this process does not occur in an 'epistemological vacuum.'[226] Ely et al argue that 'if themes 'reside' anywhere, they reside in our heads from our thinking about our data and creating links as we understand them.'[227] Moreover, identifying themes within the data may result in a substantial amount of irrelevant information, thus causing difficulties in analysis.[228]

*Deductive coding*, on the other hand, employs a top-down method.[229] This encompasses generating themes that fall within a pre-determined coding structure, or particular research categories,[230] and may be useful in locating *relevant data*.[231] Thus, depending on the type of study, a coding system may be developed on the basis of relevant theories or the research questions posed within the study.[232] On the contrary, adopting a too narrow approach may result in potentially significant data being discarded.[233] Accordingly, in some cases, inductive and deductive coding may be employed as a two-fold method, which is evident in one of the aforementioned deliberative studies in South Africa.[234] This may be advantageous in ensuring that the researcher accumulates theoretically relevant data, whilst remaining sufficiently close and true to the data.[235] As such, this study would also find benefit in adopting such an approach.

As alluded to earlier, thematic analysis does not originate from a specific epistemological tradition, but may be adapted in this respect.[236] Accordingly, it may be categorised as a realist or constructionist concept.[237] A realist perspective assumes a linear, one-directional relationship between the language within a text and the meaning or experience, where the language itself is believed to produce meaning.[238] A constructionist approach acknowledges that meaning and experience are not innate to people, but are socially constructed.[239] A middle ground between realism and constructionism is the critical realism ontology and epistemological stance, which explains that an objective reality exists

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[226] Ibid at 7.
[227] M Ely et al *On writing qualitative research: Living by words* London: Routledge/Falmer, (1997), as cited in Braun & Clarke op cit note 216 at 7.
[228] MS Linneberg & S Korsgaard 'Coding qualitative data: a synthesis guiding the novice' (2019) 19(3) *Qualitative Research Journal* 259–270 at 13 available at https://doi.org/10.1108/QRJ-12-2018-0012, accessed on 17/08/2022.
[229] Braun & Clarke op cit note 216 at 12.
[230] Ibid.
[231] Linneberg & Korsgaard op cit note 228 at 13.
[232] Ibid.
[233] Ibid at 14.
[234] Krubiner op cit note 204.
[235] Linneberg & Korsgaard op cit note 228 at 14.
[236] Braun & Clarke op cit note 216 at 4, 5.
[237] Ibid.
[238] Ibid at 14.
[239] Ibid.

independently of one's perception, but our understanding of it is shaped by individual perceptions and social factors.[240] As such, this ontology and epistemological stance would be more useful in this study.

Furthermore, in conducting thematic analyses, it needs to be decided as to whether the themes would be identified at a semantic or interpretative level.[241] At a semantic level, the identification of relevant themes occurs with reference to external meanings, thus, in congruence with what is written or spoken by participants, and without probing internal meanings.[242] Conversely, a latent approach involves the interpretation of semantic data for the identification of possible underlying ideologies, assumptions, or ideas, which may have contributed in shaping said data.[243] An integrated approach would be particularly relevant in the context of this study to understand the opinions of the participants and the underlying reasoning for their opinion changes.

Thematic analysis does not have a prescribed methodological procedure, as expressed earlier; however, Maguire and Delahunt suggest that the 6-phase model put forward by Braun and Clarke presents a 'clear and usable' thematic analysis framework.[244] This method is discussed in more detail in Chapter 3; however, interestingly, it was also supported and applied in a deliberative study on the 'quality of life' in Canada,[245] in which Fabricius, O'Doherty and Stroud had reported:

> 'We systematically read the transcripts, coding for segments of text that indicated any aspect of QoL. As per Braun and Clarke's (2006) process, we then assembled codes into meaningful groups based on our line of inquiry and developed themes. Themes that most clearly demonstrated a link to the local context were selected for inclusion within this paper.'[246]

Along with its potential advantages,[247] thematic analysis presents numerous disadvantages that need to be considered.[248] Braun and Clark claim that these disadvantages arise, to a greater extent, from poorly framed research questions or failure to carry out the

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[240] T Zhang 'Critical realism: A critical evaluation' (2023) 37(1) *Social Epistemology* 15–29 at 15.

[241] Braun & Clarke op cit note 216 at 13.

[242] Ibid.

[243] Ibid.

[244] M Maguire & B Delahunt 'Doing a Thematic Analysis: A Practical, Step-by-Step Guide for Learning and Teaching Scholars' (2017) 8(3) *AISHE-J* 3351–33514 at 3354.

[245] K Snell et al 'Investigating quality of life from the perspectives of older adults in local communities' (2022) 34(4) *Journal of Aging & Social Policy* 588–606 at 8.

[246] Ibid at 8.

[247] See table in Braun & Clarke op cit note 216 at 37.

[248] Ibid at 27.

analysis correctly, than from the methodological procedure.[249] Firstly, judging from its flexibility, thematic analysis has the ability to produce considerable amounts of differing themes; thus, the researcher may find difficulty in selecting relevant data or taking a coherent, focused approach for the execution of a richer data analysis.[250] Secondly, Lorelli et al argue that researchers may not know how to correctly go about the process, precisely in a meticulous fashion, due to thematic analysis being poorly defined and theoretically structured.[251] Thirdly, unless used within a particular epistemological paradigm or theoretical structure, Braun and Clark position that the interpretative capacity of thematic analysis is restricted to description.[252] Fourthly, even though this method is used on a wide scale, it has not gained prestige as an *analytical method*, and can be conducted by someone without the relevant expertise or knowledge.[253] Lastly, thematic analysis does not permit the researcher to judge the language used within the data or make specific claims, as with more developed analytical methods, such as discourse analysis.[254]

These limitations may affect the quality of analysis, particularly in the case of the novice researcher.[255] However, it may still be useful because it is theoretically flexible and allows for an easy application.[256] In addition, it offers a qualitative analysis methodology that may be utilised for the psychological and social interpretations of relevant data and in arranging and synthesising wide-ranging data, which may, in turn, contribute to policy development.[257] However, researchers should be guarded when adopting this method of analysis, especially in the case of complex scientific issues, such as HHGE, which require a critical data analysis. As such, this method will not be used in isolation within this study but will be integrated with other analytical guidelines to allow for such critical analysis.

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[249] Ibid.
[250] LS Nowell et al 'Thematic Analysis: Striving to Meet the Trustworthiness Criteria' (2017) 16(1) *International Journal of Qualitative Methods* 1–13 at 2 available at https://doi.org/10.1177/1609406917733847, accessed on 20/08/2022; Braun & Clarke op cit note 216 at 27.
[251] Nowell et al ibid; Braun & Clarke ibid at 4.
[252] Braun & Clarke op cit note 216 at 27.
[253] Ibid at 28.
[254] Ibid.
[255] Nowell op cit note 250 at 2.
[256] Braun & Clarke op cit note 216 at 37.
[257] Ibid.

### *(ii) Content analysis*

The early forms of *content analysis* may be traced back to the seventh century, when texts of the Old Testament were analysed using word-frequency tests.[258] In 1744, a Swedish state church employed content analysis to identify possible blasphemous segments within a series of ninety hymns, or whether they complied with religious principles.[259] According to Dovring's report, amongst the various approaches taken, particular emphasis was placed on quantifying words and phrases and their contextual usage. [260] This approach still holds utmost significance in contemporary content analysis practices.[261] Notably, it was only until the 1950s that content analysis emerged as a *consolidated analytical method* for analysing mass communications (newspapers, radio), to determine public opinion.[262] The textual content, in the form of sender, message and receiver, was quantitatively analysed for frequent, explicit features or *manifest content* to derive meaning.[263]

Content analysis is an umbrella term for numerous forms of analysis concerned with the examination of communicative content (as a basic material), including discourse analysis, conversational analysis, ethnographic analysis, etc., yet these methods may differ in their analytical objectives and the procedures used to attain such.[264] Content analysis is often utilised in 'library and information studies' (LIS), yet its versatility has allowed for its application in several fields of study,[265] and may be customised to accommodate distinct research inquiries and approaches.[266] Similar to thematic analysis, content analysis is not confined to a particular definition and has been defined differently by many authors.[267] However, the earliest definition provided by Bernard Berelson in his publication, *Content Analysis in Communication Research* (1952), has been most influential, in which he defines it as 'a research technique for the objective, systematic, and quantitative description of the manifest content of

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[258] P Mayring *Qualitative content analysis: theoretical foundation, basic procedures and software solution* Klagenfurt: SSOAR, (2014) at 18.

[259] J Macnamara 'Content Analysis' in PM Napoli (ed) *Mediated communication* De Gruyter Mouton (2018) Vol 7 at 1.

[260] K Dovring 'Quantitative semantics in 18th century Sweden Public Opinion' (1954) 19(4) *Public Opinion Quarterly* 389–394, as cited in ibid.

[261] Ibid.

[262] MD White & EE Marsh 'Content Analysis: A Flexible Methodology' (2006) 55(1) *Library Trends* 22–45 at 22; Mayring op cit note 258 at 19.

[263] Ibid at 22–23.

[264] Ibid at 23.

[265] See for examples ibid at 23.

[266] Ibid at 23.

[267] DB Prasad 'Content analysis: A method of Social Science Research' in DK Lal Das (ed) *Research Methods for Social Work* New Delhi: Rawat Publications, (2008) 174–193 at 174.

communication.'[268] Kerlinger defines it as 'a method of studying and analysing communication in a systematic, objective, and quantitative manner for the purpose of measuring variables.'[269] According to Weber, 'content analysis is a research method that uses a set of procedures to make valid inferences from text.'[270] Klaus Krippendorff, in his book, *Content Analysis: An Introduction to its Methodology,* advances a more recent, broad-based definition of content analysis,[271] where he defines it as 'a research technique for making replicable and valid inferences from texts (or other meaningful matter) to the contexts of their use.'[272]

Prasad proposes that the abovementioned definitions collectively highlight five essential features of content analysis based on inferences made on the 'sender, the message or the receiver' in the communication data.[273] These include *objectivity*, *context*, *system* and *validity*.[274] Accordingly, content analysis can be perceived as a system which analyses communication content to draw valid, objective and replicable inferences, in accordance with *inference rules* or *analytical constructs.*[275] Krippendorff expresses that these rules may be extracted from the knowledge or experience of experts, current theories or practices, and earlier research.[276] However, these inferences may only be categorised as *replicable* if quantitatively analysed.[277]

The literature reveals a historical dichotomy regarding the interpretation of content analysis as either a quantitative or qualitative method, wherein many researchers diverge in their views concerning its fundamental nature.[278] Although formerly quantitative in application,[279] content analysis has also gained recognition in qualitative studies and can be conducted through inductive or deductive enquiry.[280] In Berelson's earlier definition of content analysis (discussed above), it is unequivocal that he did not concur with this approach, as he believed that content analysis was purely quantitative in form. [281] This view was supported by

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[268] B Berelson *Content analysis in communication research* New York: The Free Press, (1952), as cited in Prasad ibid at 174.
[269] FN Kerlinger *Foundations of behavioural research* 3 ed New York: Holt, Rinehart and Winston, (1986), as cited in Prasad op cit note 267 at 174.
[270] RP Weber *Basic content analysis* New Delhi: Sage, (1985), as cited in Prasad op cit note 267 at 174.
[271] See White & Marsh op cit note 262 at 23–24.
[272] K Krippendorff *Content Analysis: An Introduction to its Methodology* (2ed) London: Sage, (2004), as cited in N Gheyle & T Jacobs 'Content Analysis: a short overview' (2017) *Internal research note* 1–17 at 2.
[273] Prasad op cit note 267 at 175.
[274] Ibid.
[275] Ibid at 175; White & Marsh op cit note 262 at 27.
[276] White & Marsh ibid at 27.
[277] See ibid at 27, 35.
[278] Macnamara op cit note 259 at 2.
[279] Y Zhang & BM Wildemuth 'Qualitative Analysis of Content' (2005) 30(7) *Human Brain Mapping* 1–12 at 1.
[280] White & Marsh op cit note 262 at 35.
[281] See Berelson op cit note 268, as cited in Macnamara op cit note 259 at 2.

many other researchers;[282] however, it was critiqued on the basis that content analysis was too simplistic to require a comprehensive, statistical approach (quantitative method).[283] Nevertheless, authors such as Kimberley Neuendorf have claimed that 'content analysis is a summarizing, quantitative analysis of messages that relies on the scientific method' which requires 'attention to objectivity-intersubjectivity, a priori design, reliability, validity, generalizability, replicability, and hypothesis testing.'[284] Notable, is her inclusion of 'intersubjectivity', which is consistent with the 'postmodern' idea that humans cannot achieve pure objectivity.[285] Furthermore, she emphasises that qualitative analysis, as a textual form of analysis, should be characterised in terms of rhetorical, discourse, interpretative, narrative and semiotic analysis, as they share similar methodological procedures.[286] However, researchers who value a qualitative approach have argued that large quantities of textual data reduced to quantitative form 'does not provide a complete picture of meaning and contextual codes, since texts may contain many other forms of emphasis besides sheer repetition.'[287]

On the other hand, several other researchers (Krippendorff, Shoemaker, Altheide, Hijams) had taken borderline positions, asserting that content analysis could be applied to quantitative and qualitative research, which were both constituents of the methodology.[288] As such, content analysis is divided into two traditions, expressed as the *behaviourist* and *humanist* traditions. [289] The *behaviourist* tradition, applied by researchers in social sciences, focuses on the impact of the content by looking ahead to determine or project the future outcome (end result) that it produces.[290] The *humanist* tradition, through the use of cultural anthropology and psychoanalysis, proceeds backwards to study what the content may reveal about society and the prevailing culture from which it originates.[291] Reese and Schoemaker posit that the behaviourist tradition is, in most part, associated with a quantitative approach, and a qualitative

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[282] See Berelson ibid at 2.

[283] S Elo & H Kyngäs 'The qualitative content analysis process' (2008) *62*(1) *Journal of advanced nursing* 107–115 at 108.

[284] K Neuendorf *The content analysis guidebook* Thousand Oaks, CA: Sage, (2002), as cited in Macnamara op cit note 259 at 2.

[285] Ibid at 2–3.

[286] Macnamara op cit note 259 at 3, 10.

[287] Ibid at 3.

[288] Krippendorff op cit note 272, P Shoemaker & S Reese *Mediating the message: Theories of influences on mass media content* White Plains, NY: Longman, (1996); DL Altheide & CJ Schneider *Qualitative media analysis* 2ed (Qualitative Research Methods) Thousand Oaks, CA: Sage, (1996). Vol 38; E Hijams 'The logic of qualitative media content analysis: A typology' (1996) 21(1) *Communications* 93–109, as cited in Macnamara op cit note 259 at 3.

[289] Macnamara op cit note 259 at 3.

[290] Ibid.

[291] Ibid.

approach is suitably embraced within the humanist tradition.[292] However, it should be noted that these traditions are not confined to such analysis techniques, but are perceived merely as complementary pairs.[293]

Some researchers, such as Berg, postulate a 'blended approach' in which quantitative and qualitative methods are utilised in content analysis and work together harmoniously, thus enriching the analysis.[294]

The second historical dispute arises from Berelson's definition of content analysis,[295] concerning whether the analysis focuses on acquiring *manifest* or *latent* content.[296] The term *manifest*, suggested by the word itself, means content (in the form of images, words, phrases, etc.) that is 'obvious' and explicit within the text.[297] The frequency of certain words or phrases within the data is essential to this analysis method.[298] In contrast, the data may contain concealed ideas or concepts, which can only be discovered through further interpretation.[299] This is referred to as latent content.[300] As Berg puts it, it involves 'an interpretive reading of the symbolism underlying the physical data'.[301] For example, within the context of this dissertation, the *reasons* why the participants changed their minds during the study constitute a form of *latent* content, since this information can only be gathered by interpreting the *manifest* content. This goes back to the quantitative-qualitative dichotomy, as presented above.[302]

Gravitating towards a quantitative-manifest paradigm, Schøder states that the 'interpretation' of data can best be avoided if the interests of the analyst lie solely within *manifest* content.[303] Krippendorff, on the other hand, fails to comprehend the rationale for the classification of content analysis as purely quantitative, even though he agrees that it should be systematic and replicable.[304] In response, Schøder claims that Krippendorff 'dismisses the exclusion of latent meanings from the researcher's legitimate horizon of interest'.[305] However,

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[292] Ibid.
[293] Shoemaker & Reese op cit note 288, as cited in Macnamara op cit note 259 at 3.
[294] B Berg *Qualitative research methods for the social sciences* 6ed Boston: Allyn & Bacon, (2007), as cited in Macnamara op cit note 259 at 3.
[295] Berelson op cit note 268, as cited in Macnamara op cit note 259 at 3.
[296] Macnamara ibid at 5.
[297] Ibid.
[298] Ibid.
[299] Ibid.
[300] Ibid.
[301] Berelson op cit note 268, as cited in Macnamara op cit note 259 at 5.
[302] Macnamara op cit note 259 at 3.
[303] K Schrøder 'Discursive realities' in K Jensen (ed) *The handbook of media and communication research* 2ed London: Sage, (2012) 106–130, as cited in Macnamara op cit note 259 at 5.
[304] Krippendorff op cit note 272, as cited in Macnamara op cit note 259 at 5.
[305] Macnamara op cit note 259 at 5.

media researchers indicate that it would be superficial and insufficient to base an understanding of the relationship between a text and its impact on mere statistical figures.[306] Thus, qualitative textual interpretation becomes more favourable in this aspect.

Content analysis involves two methods: *manual* coding by human analysts or *automated* coding (computer software).[307] The latter approach was exemplified in the DPE study on 'quality of life', as mentioned earlier. [308] Specifically, NVivo 11 Plus computer software was employed to read and code transcripts for references to 'quality of life'.[309] A comparable methodological strategy was adopted in a deliberative study conducted in the US, which examined health care decision-making and the usage of evidence. [310] The transcripts were coded using NVivo 10 software as part of a thematic qualitative analysis process.[311] It is apparent that automated coding can be applied in various analytical methodologies, including thematic analysis (as expressed in the study above), and is not restricted to content analysis alone.[312] However, in practice, automated coding poses potential methodological issues and limitations that are addressed below.[313]

De Graaf and van der Vossen present a study that tested and examined the viability of these methods based on their practical application in data analysis.[314] Accordingly, the following methodological concerns are illuminated. The study's findings indicated that manual coding served greater efficiency than automated coding when preparing and coding smaller datasets, such which may be peculiar to scholars.[315] Consequently, automated coding may only be effective in processing larger datasets (approximately 200 or more sets).[316] In addition, the incorrect preparation of datasets for importation to the coding software may result in software errors, thus becoming tedious.[317] It was also found that whilst automated systems are often

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[306] Ibid.

[307] The automated means of generating coding in content analysis is a recent development, see J Matthes & M Kohring 'The content analysis of media frames: Toward improving reliability and validity' (2008) 58 *Journal of Communication* 258–279, as cited in R de Graaf & R van der Vossen 'Bits versus brains in content analysis. Comparing the advantages and disadvantages of manual and automated methods for content analysis' (2013) 38(4) *Communications* 433–443 at 433.

[308] Snell op cit note 245 at 8.

[309] Ibid.

[310] K Carman et al 'Community Forum Deliberative Methods Demonstration: Evaluating Effectiveness and Eliciting Public Views on Use of Evidence-Final Report' (2014) at 24 available at www.effectivehealthcare.ahrq.gov, accessed on 05/09/2022.

[311] Ibid.

[312] Ibid.

[313] De Graaf & van der Vossen op cit note 307 at 1.

[314] Ibid at 1.

[315] Ibid at 438.

[316] Ibid.

[317] Ibid.

associated with objectivity, this was not the case within the study.[318] This is because analysts were required to perform a significant amount of data interpretation, prior to and during the coding process, becoming a highly subjective procedure.[319] Moreover, the system may be biased, as it cannot identify synonyms or successfully distinguish between words in their contextual use (words of the same meaning, but used in differing contexts), as would be possible in manual coding.[320] Issues of reliability also arise, concerning the system's inability to process non-electronic text formats, and problems of imprecision may occur when these files are converted into electronic text formats.[321] Lastly, the lack of a unanimous statistical standard within the system results in differing criteria being applied amongst scholars, which means that the results may only be applicable in certain studies and not all.[322]

Despite these methodological challenges, automated coding systems may still prove beneficial if applied in conjunction with manual methods to confirm the findings within a manual system.[323] Since the dataset is relatively small, this study would find efficiency and suitability in employing a manual coding system; however, a software program may still be used to corroborate the findings.

### *(b) Changes in public opinion*

Deliberative theorists argue for the 'transformative power' of DPE, where it is believed that deliberative discussions have the capacity to influence ideas and consequently invoke opinion reformulation or change.[324] Particularly, Chambers outlines that the deliberative process is a 'discussion aimed at producing reasonable, well informed opinions.'[325] Additionally, many deliberative studies corroborate that participation in deliberative discussion may lead to altered policy perspectives.[326] This suggests that opinion change may be induced by deliberative

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[318] Ibid.
[319] Ibid.
[320] Ibid.
[321] Ibid.
[322] Ibid.
[323] Ibid.
[324] JS Dryzek & V Braithwaite 'On the Prospects for Democratic Deliberation: Values Analysis Applied to Australian Politics' (2000) 21(2) *Political Psychology* 241–266 at 242, as cited in J Suiter, DM Farrell & E O'Malley 'When do deliberative citizens change their opinions? Evidence from the Irish Citizens' Assembly' (2014) 37(2) *International Political Science Review* 1–15 at 2.
[325] S Chambers 'Deliberative democratic theory' (2003) 6(1) *Annual Review of Political Science* 307–326. at 309, as cited in Suiter, Farrell & O'Malley ibid at 2.
[326] JS Fishkin *The Voice of the People: Public Opinion and Democracy* New Haven, CT: Yale University Press, (1997); JS Fishkin *When the People Speak: Deliberative Democracy and Public Consultation*. Oxford: Oxford University Press, (2009); RC Luskin, JS Fishkin & R Jowell 'Considered Opinions: Deliberative Polling in Britain' (2002) 32 *British Journal of Political Science* 455–487; KM Hansen & V Andersen 'Deliberative Democracy and Deliberative Poll on the Euro' (2004) 27(3) *Scandinavian Political Studies* 261–286; M Setälä, K Grönlund & K Herne 'Citizen Deliberation on Nuclear Power: A Comparison of Two Decision-making

reasoning or when deliberants are exposed to differing viewpoints and new information.[327] This accords with Habermas's contention that deliberants may alter their viewpoints in light of 'the forceless force of the better argument.'[328] Stark claims that it is these facets which make DPE unique and worthwhile when policy decisions come to the fore, as expressed earlier.[329]

Deliberants may reach agreement for various reasons, as Bohmen points out, to accommodate or appease other views; to seek 'reasoned agreement'; or out of 'other-regarding participants compromise.'[330] Opinion change may also be subsequent to deliberants endorsing a neutral perspective, in compromise of pre-existing opinions.[331] On the contrary, DPE may have little to no effect on opinion reformulation, considering Chamber's argument that deliberants may participate with pre-existing opinions or ingrained attitudes, which may persist until the end of the engagement.[332] This occurs when they adopt more extreme positions during the deliberative discussions, thus resulting in polarisation.[333] This was particularly evident in a deliberative study on GGE conducted in the Netherlands, where an inquiry was pursued on the impact of DPE on opinion change.[334] As per the results of the study, there was no evidence discovered for the conclusion that deliberative dialogue had resulted in altered acceptance rates, although a faint indication that it may have produced fewer negative opinions on GGE, when deliberants were exposed to new knowledge.[335] The deliberations had, however, been effective in developing first opinions, creating greater awareness on the potential issues surrounding GGE, establishing a better understanding of the views of other participants and reinforcing pre-existing opinions.[336]

On the other hand, a deliberative study in Finland proved that opinion change can be influenced by deliberative content alone.[337] In the study, the deliberants with greater levels of

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Methods' (2010) 58(4) *Political Studies* 688–714, as cited in S Himmelroos & HS Christensen 'Deliberation and Opinion Change: Evidence from a Deliberative Mini-public in Finland' (2013) 37(1) *Scandinavian Political Studies* 41–60 at 41–42.

[327] Himmelroos & Christensen ibid at 42.

[328] J Habermas *Theory of Communicative Action, Volume 1: Reason and the Rationalization of Society* Cambridge: Polity Press, (1981), as cited in ibid at 44.

[329] Stark, Thompson & Marston op cit note 185 at 454.

[330] J Bohman *Public Deliberation. Pluralism, Complexity and Democracy* Cambridge, MA: MIT Press, (1996), as cited in ibid at 43.

[331] Himmelroos & Christensen op cit note 326 at 43.

[332] S Chambers *Reasonable Democracy: Juergen Habermas and the Politics of Discourse*. Ithaca, NY: Cornell University Press, (1996), as cited in Himmelroos & Christensen op cit note 326 at 43.

[333] Himmelroos & Christensen op cit note 326 at 43.

[334] D Houtman et al 'Changes in opinions about human germline gene editing as a result of the Dutch DNA-dialogue project' (2022) *European Journal of Human Genetics* 1-8 at 1.

[335] Ibid at 7.

[336] Ibid.

[337] Himmelroos & Christensen op cit note 326.

deliberative reasoning were more likely to alter their opinions by reassessing their thinking, in consideration of other viewpoints.[338] Furthermore, it was found that opinions that were more firmly situated were less susceptible to change than unsteady opinions.[339] As such, the literature divulges that shifts in opinion cannot be explained by a single all-encompassing theory; accordingly, these reasons are variable and may be attributable to various other factors, including demographic components (gender, education, knowledge, age or differences in personality).[340]

In discussing these demographic components, it is worth noting that many scholars differ on the impact of said factors on opinion change.[341] To provide examples, Hummelroos et al state that these factors may be influential in a 'mini public' setting.[342] Luskin et al and Setäla et al claim that such factors contribute a minor role in opinion change.[343] In contrast, other scholars indicate that factors such as age or education may have some effect on opinion reformulation.[344] Converse and Zaller have also advanced that prior awareness of deliberative issues or greater knowledge may result in minor opinion changes due to more developed attitudes.[345] Moreover, Karpowitz and Mendelberg propose that opinions may be informed by the group's social dynamics.[346] Several demographic factors proved significant in a deliberative study conducted in Ireland, which revealed that opinion changes occurred more frequently among deliberants who were younger (under 65s), with lower levels of knowledge.[347] Conversely, among older participants (over 65s) with greater knowledge levels, opinion shifts were minimal or non-existent, particularly when discussing prominent issues.[348] While the above factors may be useful in explaining why opinions had changed, they may have limited utility in informing policy formulation. In contrast, the aforementioned deliberative study on policy analysis conducted in Australia demonstrated that reasoning premised on deliberative content, specifically, justifications based on arguments presented by fellow

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[338] Ibid at 54–55.

[339] Ibid at 55.

[340] Ibid; Suiter, Farrell & O'Malley op cit note 324 at 3.

[341] Suiter, Farrell & O'Malley ibid at 3.

[342] Himmelroos & Christensen op cit note 326, as cited in ibid 3.

[343] Setälä, Grönlund & Herne op cit note 326; Luskin, Fishkin & Jowell op cit note 326, as cited in Suiter, Farrell & O'Malley op cit note 324 at 3.

[344] Suiter, Farrell & O'Malley ibid.

[345] P Converse 'The Nature of Belief Systems in Mass Publics' in A Apter (ed) *Ideology and Discontent* New York: Free Press (1964); J Zaller *The Nature and Origins of Mass Opinion* Cambridge: Cambridge University (1992) as cited in Himmelroos & Christensen op cit note 326 at 45.

[346] CF Karpowitz & T Mendelberg 'Groups and Deliberation' (2007) 13 *Swiss Political Science Review* 645–662, as cited in Himmelroos & Christensen op cit note 326 at 45.

[347] Suiter, Farrell & O'Malley op cit note 324 at 11.

[348] Ibid.

participants, holds greater epistemological significance[349] and may be more beneficial to policymakers.[350] As such, the main focus of this dissertation is on the underlying reasoning for opinion changes based on deliberative content, which would be more enriching to the study.[351]

### *(c) The arguments for and against HHGE*

This section examines the results of public engagement efforts and explores the essential arguments for and against HHGE, as presented by various researchers. By analysing these perspectives, this review aims to provide a balanced understanding of the ongoing policy, ethical and scientific discourse surrounding genome editing.

### *(i) Public opinion studies*

These studies divulge that global public opinion is generally receptive to certain HHGE applications, which are precisely *therapeutic* in nature, while indicating hesitancy regarding non-therapeutic enhancements.[352] In 2017, a survey by the Royal Society found that 76% of UK adults supported genome editing to correct genetic disorders in a way that ensures the correction is passed on to future generations.[353] In a similar vein, Associated Press-NORC Center for Public Affairs Research (AP-NORC) has revealed that 71% of Americans had favoured HHGE to prevent the inheritance of 'incurable or fatal' health conditions.[354] Moreover, a recent PEW Research study, conducted across 20 countries, found comparable levels of support for genome editing to prevent the birth of children with serious genetic conditions.[355]

As such, public opinion studies reveal that support for therapeutic HHGE applications is often contingent on the perceived *severity* of the condition, with more serious diseases garnering greater acceptance.[356] This pattern was observed across various public engagement studies, where participants indicated their support for genome editing on the grounds that it

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[349] Himmelroos & Christensen op cit note 326 at 54.
[350] Stark, Thompson & Marston op cit note 185 at 459.
[351] Ibid.
[352] Thaldar et al op cit note 92 at 4.
[353] Ibid.
[354] Ibid.
[355] Ibid.
[356] See A Jedwab et al 'Genetics experience impacts attitudes towards germline gene editing: A survey of over 1500 members of the public' (2020) 65(12) *Journal of Human Genetics* 1055–1065 as cited in Thaldar et al op cit note 92 at 13; see L Hoffman-Andrews et al 'Attitudes of people with inherited retinal conditions toward gene editing technology' (2019) 7(7) *Molecular Genetics & Genomic Medicine* 1– 14; S Segers 'Heritable genome editing: ethical aspects of a developing domain' (2023) 38(11) *Human Reproduction* 2055– 2061 at 2058.

could prevent or treat life-threatening or debilitating health conditions.[357] For example, 67% of Americans in an AP-NORC study endorsed the use of HHGE to lower the risk of severe, life-threatening conditions, such as cancer.[358] Additionally, while roughly 12% opposed, a global online survey of 10, 067 respondents revealed that about 63% of them were in support of HHGE to prevent life-threatening diseases.[359]

Conversely, if the condition was not sufficiently life-threatening, it was supported for its perceived impact on quality of life.[360] Research among the Dutch public indicated that the technology was valued for its ability to enhance the quality of life of individuals and their families.[361] Echoing this sentiment, a key recommendation from an Australian citizens' jury provided that genome editing could 'alleviate human suffering', further supporting its promise to improve the quality of life. [362] On the other hand, a PEW Research Center study divulged that only 39% of the American public believed that using genome editing to lower the risk of serious health conditions could enhance a prospective individual's quality of life, where 40% of the participants stated that it would have no impact.[363] It may be interesting to note that 18% of Americans felt that the overall quality of life could worsen.[364] A significant finding, as demonstrated in another study, is that the adverse impact of serious conditions on quality of life was frequently overstated by individuals who do not experience these health conditions.[365] In contrast, individuals with chronic illnesses and disabilities tend to have a more positive perception of their quality of life than their families, healthcare providers, or the general public.[366]

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[357] Thaldar et al op cit note 92 at 4; T McCaughey et al 'A global social media survey of attitudes to human genome editing' (2016) 18(5) *Cell stem cell* 569– 572.

[358] Thaldar et al op cit note 92 at 4.

[359] McCaughey et al op cit note 357.

[360] I van Dijke et al 'The ethics of clinical applications of germline genome modifications: a systematic review of reasons' (2018) 33(9) *Human Reproduction* 1777–1796 at 1779.

[361] S Hendriks et al 'Reasons for being in favour of or against genome modification: a survey of the Dutch general public' (2018) (3) *Human Reproduction Open* 1–12 at 6, 7.

[362] D Nicol et al 'Genome editing: Formulating an Australian community response: Report to decision makers, stakeholders, and members of the public' (2022) at 20 available at https://www.utas.edu.au/__data/assets/pdf_file/0011/1634258/OP12-final-report.pdf, accessed on 07/04/2024.

[363] Pew Research Center 'AI and Human Enhancement: Americans' Openness is Tempered by a Range of Concerns' (2022) available at https://www.pewresearch.org/wp-content/uploads/sites/20/2022/03/PS_2022.03.17_AI-HE_REPORT.pdf accessed on 07/04/2024 at 75.

[364] Ibid.

[365] Hoffman-Andrews et al op cit note 356 at 11.

[366] Ibid at 11.

As demonstrated above, public approval of HHGE was strongly influenced by its intended purpose, with higher acceptance for applications focused on medical necessity.[367] To illustrate, a Japanese study found that support for genome editing was significantly higher when directed towards treating or preventing life-threatening or debilitating diseases.[368] Furthermore, whether a condition was genetic or infectious, its perceived severity was a primary factor influencing the acceptance of genome editing.[369] For instance, Jedwab et al reported that 65% of participants across 67 countries supported the use of HHGE to confer resistance against infectious diseases, citing their recognised severity.[370] However, in other regions, such applications were viewed as 'immoral' and potentially setting a precedent for a 'slippery slope' towards non-therapeutic genetic enhancements.[371]

Importantly, several public opinion studies emphasise the context-dependent nature of these perceptions. In a Dutch study, for instance, one participant remarked that support for genome editing in infectious diseases, such as HIV, would only be considered if the disease was prevalent in their country, stating: 'If I would live in a country where HIV is more prevalent'.[372] This suggests that the severity of a health condition may be influenced by 'country-specific' contextual factors.[373] In the context of our study, it can be anticipated that South African respondents would perceive diseases such as TB, HIV/AIDS, and COVID-19 as particularly severe, owing to their high mortality rates and epidemic nature.[374]

On the other hand, public opinion studies generally display lower levels of support for HHGE when aimed at non-therapeutic enhancements, such as intelligence or personality traits. This has been evidenced in various studies, including a US study where acceptance was significantly lower for enhancing intelligence and other attributes (such as eye colour).[375] These findings were similar to those of a UK study, in which HHGE for cosmetic enhancements

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[367] T Sawai et al 'Human genome editing in clinical applications: Japanese lay and expert attitudes' (2023) 14 *Frontiers in Genetics* 1– 15 at 11.

[368] Ibid.

[369] EL Howell et al 'What do we (not) know about global views of human gene editing? Insights and blind spots in the CRISPR era' (2020) 3(3) *The CRISPR Journal* 148–155, as cited in Thaldar et al op cit note 92 at 4.

[370] Jedwab et al op cit note 356.

[371] Thaldar et al op cit 92 at 14.

[372] Hendriks et al op cit note 361 at 8.

[373] Thaldar et al op cit note 92 at 14.

[374] Thaldar et al op cit 92 at 14; Statistics South Africa 'TB tops of death in SA in 2018' available at https://www.statssa.gov.za/?p=14435, accessed on 10/05/2024; World Health Organization 'Tuberculosis' 29 October 2024 available at https://www.who.int/news-room/fact-sheets/detail/tuberculosis, accessed on 10/05/2024; C Olivier & L Luies 'WHO goals and beyond: managing HIV/TB co-infection in South Africa'(2023) 5(1) *SN Comprehensive Clinical Medicine* 1–13 at 2, 1. SAMRC 'Special report: Over 125,000 excess deaths during the COVID-19 pandemic' *Press Releases* 28 January 2021 available at https://www.samrc.ac.za/press-releases/special-report-over-125000-excess-deaths-during-covid-19-pandemic, accessed on 10/05/2024.

[375] Thaldar et al op cit note 92 at 14.

received minimal support.[376] In addition, PEW research has divulged that 82% of the global public believed that genetically enhanced intelligence was 'a misuse of technology'.[377]

*(ii) The scholarly perspective*

In referencing the work of Richter and Baccheta, Almeida and Ranisch collate arguments for and against HHGE under three categories of consideration: pragmatic, socio-political, and categorical.[378] Pragmatic considerations are centred on the medical and technological impacts of HHGE, such as consequences relating to efficacy, safety and the associated risk-benefit ratio.[379] Socio-political considerations focus on all societal impacts of HHGE, such as the reduction or furtherance of societal inequalities and the influence on power asymmetries.[380] Categorical considerations are concerned with incorporating deontic logic, which argues that HHGE should not be practised due to the absence of consent from future generations and moral obligations.[381]

*Pragmatic considerations*

Among others, one of the more significant arguments for HHGE, in the pragmatic context, is that it can be used to reduce illnesses and diseases that are preventable by way of gene editing.[382] On the other hand, Furtado maps out controversies surrounding HHGE by drawing findings from three categories of sources: scientific articles, institutional statements, and the 2015 International Summit on Gene Editing.[383] He refers to the works of UNESCO, Collins and Lanphier et al, who propose that HHGE, whilst showing promise, introduces immeasurable safety and medical risks, such as random genome mutations having far-reaching consequences for future generations.[384] While the study operated under the assumption that HHGE would achieve a sufficient level of safety and effectiveness by the time it reaches clinical application (if at all), it remains crucial to briefly consider these pragmatic concerns.

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[376] Ibid.

[377] C Funk et al 'Biotechnology research viewed with caution globally, but most support gene editing for babies to treat disease' *Pew Research Center Science & Society* (2020) available at https://www.pewresearch.org/science/2020/12/10/biotechnology-research-viewed-with-caution-globally-but-most-support-gene-editing-for-babies-to-treat-disease/, accessed on 11/05/2024.

[378] M Almeida & R Ranisch 'Beyond safety: mapping the ethical debate on heritable genome editing interventions' (2022) 9(1) *Humanities & Social Sciences Communication* 1–14 at 7.

[379] Ibid.

[380] Ibid.

[381] Ibid.

[382] Ibid at 2.

[383] RN Furtado 'Gene Editing: The Risks and Benefits of Modifying Human DNA' (2019) 27(2) *Revista Bioética* 223–233.

[384] Ibid at 226.

Examples of such genomic mutations can be found in the work of Turocy, Adashi and Egli, who reported that CRISPR-Cas9 caused frequent changes in the chromosomes of human embryos.[385] To support this statement, they refer to the work of Zuccaro et al, who investigated using CRISPR-Cas9 to target a mutation that causes blindness in the EYS gene and found that DNA breaks remained unrepaired in more than half of the human embryos that were tested.[386] The potential risks carried by the modified individual are added by Furtado, by referring to the outcomes of the International Summit on Gene Editing.[387] During the summit, caution was raised on the fact that genes serve multiple functions and knock-on effects may occur with the editing of genes, potentially resulting in unfavourable consequences.[388] Similar to these scholars, Critchley et al assert that a major concern is that future generations may inherit an unintended or harmful modification.[389] According to the Nuffield Council, it is this aspect of heritability which further intensifies concerns.[390] To further illustrate this point, the National Academies of Sciences, Engineering, and Medicine provides evidence that the chances of HIV infection are reduced by editing the CCR5 gene; however, the individual becomes more susceptible to the West Nile virus.[391] The Parliamentary Office of Science and Technology provides more evidence of the unintended loss of beneficial characteristics through the use of HHGE, whereby immunity to Malaria is linked to carriers of sickle cell disease, thereby editing the gene to avoid or mitigate the chances of developing sickle cell disease also carries the possibility of losing the beneficial variant of said gene.[392]

For some scholars, these risks may be considered acceptable if they prevent a serious disease rather than a 'trivial' one; thus, the application of genome editing for less severe health conditions may involve certain trade-offs.[393]

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[385] J Turocy, EY Adashi & D Egli (2021) 'Heritable Human Genome Editing: Research Progress, Ethical Considerations, and Hurdles to Clinical Practice' (2021) 184(6) *Cell* 1561–1574 at 1565.

[386] Ibid.

[387] Furtado op cit note 383 at 227.

[388] Ibid.

[389] C Critchley et al 'Predicting public attitudes toward gene editing of germlines: the impact of moral and hereditary concern in human and animal applications' (2019) 9(704) *Frontiers in Genetics* 1–14 at 12.

[390] Nuffield Council on Bioethics op cit note 17 at 113.

[391] National Academies of Sciences, Engineering and Medicine. (2015) 'International Summit on Human Gene Editing: A Global Discussion' (2015) at 1–8 available at https://www.ncbi.nlm.nih.gov/books/NBK343651/, accessed on 07/10/2024.

[392] The Parliamentary Office of Science and Technology '*Human Germline Genome Editing'* (2020) *PostNote* at 4 available at https://post.parliament.uk/research-briefings/post-pn-0611/, accessed on 09/10/2024.

[393] I van Dijke et al 'Should germline genome editing be allowed? The effect of treatment characteristics on public acceptability' (2021) 36(2) *Human Reproduction* 465–478 at 467.

### *Socio-political considerations*

#### *Discrimination and inequalities*

The promotion of discrimination and inequalities forms a significant argument against HHGE in the socio-political context.[394] Attempts to prevent disabilities through HHGE may lead to the development of a culture of desirable and undesirable traits, which may spawn a negative view of disabled persons and accelerate social division.[395] Furthermore, by referring to the ideology of ableism, Benjamin put forth similar concerns that HHGE has the potential to cause discrimination within society, whereby HHGE would reinforce social norms with the possible consequence of people with disabilities becoming devalued in society.[396] In his opinion, this practice could promote societal views that disabilities are inherently undesirable and ought to be prevented.[397] The expressivist critique further deepens this argument by asserting that HHGE, particularly when used to prevent disabilities, conveys a pessimistic view of the disability and individuals who live with them.[398] Nevertheless, the Nuffield Council explicitly dismisses this objection, precisely when it pertains to genetic conditions that severely impact both the quality of life and life expectancy.[399] Other scholars have also contended that HHGE is primarily a health-focused intervention aimed at addressing medical conditions rather than making value judgments about disabilities or those living with them.[400] Similarly, Savulescu maintained that choosing to eliminate specific health conditions does not inherently amount to discrimination or the devaluing of individuals with such conditions.[401]

An additional socio-political consideration among scholars is the potential for HHGE to exacerbate existing health inequalities and increase the divide between the rich and poor.[402] The fundamental cause theory in public health doctrine suggests that individuals with greater access to resources, such as wealth, education and advanced medical technologies, are able to

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[394] J Delhove et al 'Public acceptability of gene therapy and gene editing for human use: a systematic review' (2020) 31(1-2) *Human gene therapy* 1–34 at 20.

[395] C Gyngell, H Bowman-Smart & J Savulescu 'Moral reasons to edit the human genome: picking up from the Nuffield report' (2019) 45(8) 514– 523 at 517; A Nordberg & L Antunes 'Genome editing in humans: A survey of law, regulation and governance principles' *European Parliamentary Research Service* 3 June 2022 at 10 available at https://www.europarl.europa.eu/thinktank/en/document/EPRS_STU(2022)729506, accessed on 18/05/2024.

[396] R Benjamin 'Interrogating equity: a disability justice approach to genetic engineering' (2016) 32(3) *Issues in Science and Technology* 51– 54 at 53.

[397] Ibid.

[398] Gyngell, Bowman-Smart & Savulescu op cit note 395 at 517.

[399] Ibid.

[400] Almeida & Ranisch op cit note 378 at 10.

[401] Ibid.

[402] Ibid at 7; C Brokowski 'Do CRISPR germline ethics statements cut it?' *The CRISPR journal* (2018) 1(2) 115–125 at 116.

secure better health outcomes than those with fewer resources.[403] This theory suggests that technological advancements, like HHGE, could reinforce systemic disparities by disproportionately benefiting privileged groups while leaving marginalised populations behind.[404] These beliefs were shared by authors such as Massey, who expressed concerns that 'designer baby technology' would, in theory, enable the wealthy to enhance their children, giving them an unfair disadvantage over children from families who could not afford HHGE.[405] As such, the literature presents a fundamental ethical dilemma that HHGE would not be equally accessible to everyone once made available, thereby exacerbating socio-economic divisions.[406] For some scholars, this presents an 'acute risk' in countries, such as South Africa, where there is a significant gap between the rich and poor.[407] According to Shozi, this is a compelling justification to prohibit HHGE altogether.[408]

In terms of long-term impacts, Chen suggests that eugenics, by way of HHGE, has the potential to hasten social, political, and economic stratification, the ramifications of which would be arduous to reverse.[409] To elucidate on this point, Chen provides an argument in the form of an example, which suggests that if the genes for a higher intellect are identified and the costs involved with HHGE were sufficiently high, affluent families would have genetic advantages extending through their lineage.[410] Additionally, Gyngell, Bowman-Smart and Savulescu further express concern regarding the integrity of genetic inheritance, whereby HHGE may interfere with or break the line of inheritance that links families together.[411]

### *Implications for genetic variation*

Kandler, Richter and Zapko-Willmes state that approximately 40% to 50% of variation in personality traits is attributable to genetic variation.[412] In connection, some scientists and scholars caution that if physical or personality traits can be modified using HHGE, it could

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[403] AM Subica 'CRISPR in public health: the health equity implications and role of community in gene-editing research and applications' (2023) 113(8) *American Journal of Public Health* 874–882 at 877.

[404] B Shozi & D Thaldar 'Promoting equality in the governance of heritable human genome editing through Ubuntu: Reflecting on a South African public engagement study' (2023) 23(7) *The American Journal of Bioethics* 43–49 at 43.

[405] E Massey 'Ethical Debate on Gene Editing on Embryos' (2020) 13 *University Library Prize Finalists for First Year Seminars* 1–10 at 5.

[406] Shozi & Thaldar op cit note 404 at 43.

[407] Ibid.

[408] Ibid.

[409] WW Chen 'Human Germline Gene Editing: Engineering an Unstoppable Train' (2019) 28(523) *Southern California Interdisciplinary Law Journal* 523–548 at 534–548.

[410] Ibid.

[411] Gyngell, Bowman-Smart & Savulescu op cit note 395 at 517.

[412] C Kandler, J Richter & A Zapko-Willmes 'Genetic Basis of Personality Traits' (2017) *Springer International Publishing* 1–29 at 2.

reduce genetic variation or diversity.[413] Resnik and Vorhaus add to this argument, suggesting that this loss of genetic diversity could also extend to cultural diversity. [414] Youvan provides that, although HHGE shows great potential, it remains in its early stages, and such risks are not yet fully revealed by scientists.[415]

Kirby, in citing Rifkin, warns that such genomic interventions could lead to a form of homogeneity with little phenotypic variation in society.[416] For Youvan, this could be at the expense of significant values, such as individuality and identity, where genetic traits are 'carefully curated and controlled'.[417] He argues further that reducing genetic variation could subsequently erode the 'richness' and 'creativity' of the human experience, resulting in a form of 'genetic perfection'.[418] Scholars, like Alonso, imagine a dystopian future where diversity is reduced and populations resemble 'quasi-clones', characterised by uniformity.[419] However, re-evaluating his position, he asserts that this may be theoretically unlikely in current liberal societies.[420] In referring to the works of Powell, he provided that there is no single concept of what is universally 'good', suggesting that parents will not select the traits of their children according to a single criterion, and genetic variation may still be present.[421]

According to Mill's notion of 'experiments in living', genome editing technologies similarly allow for 'experiments in reproduction'.[422] To elucidate this concept, parents already make choices for their children in the realm of education, based on the skills and values they wish to instil in them, and have also proven to prioritise different skills or traits.[423] However, Gyngell argues that there may still be some desirable traits which are uniformly observed, and

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[413] DC Youvan 'The Ethics of Genetic Enhancement: Examining the Societal Consequences of Unregulated Gene Editing for the Elite' (2024) 1–30 at 8 available at https://www.researchgate.net/publication/384598399, accessed on 10/11/2024; COGEM/Health Council of the Netherlands 'Editing Human DNA: Moral and social implications of germline genetic modification'(2017) at 33 available at https://cogem.net/app/uploads/2019/07/Germline-Modification1.pdf, accessed on 09/11/2024; M Alonso 'Post genetic revolution dynamics. How will modified and unmodified humans coexist?' (2024) 72 *Enrahonar. An international journal of theoretical and practical reason* 35–54 at 41

[414] DB Resnik & DB Vorhaus 'Genetic modification and genetic determinism' (2006) 1(9) *Philosophy, ethics, and humanities in medicine* 1–11 at 5.

[415] Youvan op cit note 413 at 8.

[416] DA Kirby 'The New Eugenics in Cinema: Genetic Determinism and Gene Therapy in *GATTACA*' (2000) 27(2) *Science Fiction Studies* 1–27 at 5.

[417] Youvan op cit note 413 at 12.

[418] Ibid at 8, 12.

[419] Alonso op cit note 413 at 41.

[420] Ibid.

[421] Ibid.

[422] Ibid.

[423] Ibid.

reductions in diversity can be expected.[424] On the other hand, Resnik and Vorhaus contend that genetic composition plays a lesser role in shaping personal identity than what is expected by critics.[425] The concept of uniqueness may be unimportant to individuals, where their individuality is also shaped by environmental and personal experiences, making genetic uniqueness less significant.[426]

Gyngell, Bowman-Smart and Savulescu further raised that if personality traits are genetically altered, there may exist an imbalance in society, such as promoting extroversion or introversion in individuals.[427] It is further explained that introverts make contributions to society that extroverts may not, such as forms of cognitive diversity which may promote problem-solving, and achievements in sciences and the arts.[428] This concern may be supported by the work of Sword, who suggest that 'more than 75% of people with an IQ above 160 are introverted'.[429]

Bioethicists have also expressed concerns that genetic traits deemed undesirable by society, yet still valuable, could be entirely removed from the human population.[430] According to Gyngell, some conditions currently classified as disorders and sometimes undesirable may, in fact, offer unique forms of cognitive diversity.[431] Youvan further emphasises the complexity of genetic interactions, arguing that 'genes do not act in isolation', and 'altering one gene could have ripple effects on others'.[432] Thus, highlighting the potential unintended consequences of genetic modifications. Supporting this view, Gyngell highlights the importance of immuno-diversity– the variation in genes that influence innate immunity, which enhances a population's adaptability to diseases.[433] In a separate study, he cautions that while modifying innate immunity may benefit individual children, it could also have negative societal consequences.[434] A widespread preference for certain immune genes, for instance, could increase susceptibility

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[424] C Gyngell 'Enhancing the Species: Genetic Engineering Technologies and Human Persistence' (2012) 25(4) *Philosophy and Technology* 495–512, as cited in ibid.

[425] Resnik & Vorhaus op cit note 414 at 9.

[426] Ibid.

[427] Gyngell, Bowman-Smart & Savulescu op cit note 395 at 518.

[428] Ibid.

[429] LK Sword, 'The Gifted Introvert' (2000) *Gifted & Creative Services* Australia 1–5 at available at *https://www.yumpu.com/en/document/view/15127148/the-gifted-introvert-by-lesley-sword-starjump,* accessed on 13/11/2025.

[430] Kirby op cit note 416 at 5.

[431] C Gyngell 'Gene editing and the health of future generations' (2017) 110(7) *Journal of the Royal Society of Medicine* 276–279 at 278.

[432] Youvan op cit note 413 at 8.

[433] Gyngell op cit note 424 at 278.

[434] Gyngell, Bowman-Smart & Savulescu op cit note 395 at 518.

to emerging pathogens in the future.[435] Similarly, Youvan indicated the 'long-term evolutionary consequences' of genome editing.[436] He emphasises that reducing genetic diversity, an essential factor for societal adaptability and resilience, could ultimately increase society's vulnerability to infectious diseases.[437]

*Nature vs Nurture*

Another notable argument in the literature put forth by Kirby is that the idea of genetic enhancements leading to homogeneity or the loss of diversity is rooted in the belief that 'all traits are genetically determined'.[438] In this regard, Resnik and Vorhaus indicate that most objections to genomic enhancements rest on this misconception.[439]

Aside from the genome editing context, the literature reflects a long-standing debate as to whether genes or the environment are responsible for the expression of certain traits, or nature vs nurture.[440] Being the first to frame the debate in these terms, Galton argued that when environmental differences are minimal among individuals of the same race in the same country, it is ultimately nature which is dominant.[441] In support of this view, more recent scholars, like Scarr, through the use of twin studies, have indicated that the environment is determined by the characteristics of individuals.[442] As a result, it is only nature and not nurture that would have an influence on genes.[443] Conversely, Watson, in his research, revealed that behavioural traits can be cultivated or learned.[444] Some scholars have also asserted that being exposed to specific environmental factors can result in 'permanent genetic changes' and could also have a lasting impact on the expression of genes.[445] Moreover, engaging in novel experiences can stimulate brain growth.[446] Despite attempts to provide definitive answers, Reese positions that most studies have failed in this respect, leading to conclusions that both nature and nurture are significant in gene expression.[447]

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[435] Ibid.

[436] Youvan op cit note 413 at 8.

[437] Ibid at 15.

[438] Kirby op cit note 416 at 5–6.

[439] Resnik & Vorhaus op cit note 414 at 9.

[440] KA Reese 'Nature v Nurture: The Timeless Debate' (published Honors thesis, Kingsborough Community College, 2019) at 3.

[441] CR Badcock 'Nature-nurture controversy, history of' in JD Wright (ed) & D. James *International Encyclopedia of the Social & Behavioral Sciences* (2015) 340–344 at 340.

[442] Ibid at 4.

[443] Ibid.

[444] Ibid at 6.

[445] Reese op cit note 440 at 10.

[446] Ibid.

[447] Ibid at 7.

Proponents of the nature argument lean more towards genetic determinist assumptions.[448] Genetic determinism states that personality, behaviour and physical attributes are solely attributable to genes or genetic factors.[449] In this respect, Resnik and Vorhaus distinguished between three variations of the concept.[450] Strong genetic determinism indicates that genes will almost always result in a particular trait.[451] According to moderate genetic determinism, a gene increases the chances of a trait occurring, making it more likely than not.[452] Weak determinism suggests that a gene influences the likelihood of a trait but does not guarantee its development, as the probability remains low.[453]

These beliefs have given rise to the *authenticity* argument, where it is stated that certain genetic enhancements could reduce the 'authenticity' of an individual's talents or accomplishments.[454] As such, one's talents are not perceived as his own but merely the outcome of the genetic enhancement.[455] Resnik and Vorhaus have opposed, what they called, strong determinist assumptions, on the grounds that specific environmental factors are still necessary to give full effect to specific talents or skills.[456] To elucidate this point, an individual with a particular ability or talent (genetically enhanced or natural) cannot be a 'passive subject' in its development.[457] Thus, a level of hard work and dedication would still be required to attain success.[458]

### *Categorical considerations*

Categorical considerations may be extended to the moral obligations of parents who wish to pursue HHGE–in this context, the issue of the offspring's autonomy arises.[459] Nordberg and Antunes address this issue by referring to Habermas and Sandel, who argue that third parties should not hold the power of autonomy over their descendants and should act in a way that will not deprive said descendants of being the 'authors of their own lives'.[460] Thus, while proponents of HHGE may frame it as a means of preventing disease and improving health,

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[448] Kirby op cit note 416 at 6.
[449] Ibid.
[450] Resnik & Vorhaus op cit note 414 at 3.
[451] Ibid.
[452] Ibid.
[453] Ibid.
[454] Ibid at 8.
[455] Ibid.
[456] Ibid 8–9.
[457] Ibid at 8.
[458] Ibid at 8–9.
[459] Nordberg & Antunes op cit note 395 at 11.
[460] Ibid.

scholars, like Smolenski, have reservations regarding the inability of future generations to consent to an intervention that could undermine their future autonomy.[461] This concern is closely linked to the foundational principle of informed consent in medical ethics.[462]

In contemporary bioethics, the right to autonomy and self-determination are regarded as fundamental rights, extending to all individuals, including children.[463] Accordingly, Almeida and Ranisch emphasise that individuals should be able to make decisions regarding their own bodies, highlighting the importance of safeguarding physical integrity.[464] These rights are given effect through informed consent in modern healthcare systems.[465] According to Beauchamp and Childress, informed consent ensures that individuals are able to make autonomous and informed decisions based on a clear understanding of the potential risks and benefits of a particular medical procedure.[466] However, HHGE challenges this principle, preventing future individuals from making a decision that could impact their future autonomy, and shifting the decision-making power entirely to the current generation or their parents.[467] Habermas's critique of genetic enhancement, as presented in *The Future of Human Nature*, argues that such interventions risk diminishing the self-authorship of prospective individuals– the ability to perceive oneself as the main 'author' of one's own life, consistent with autonomy.[468] He emphasised that the ability of 'self-authorship' is necessary in developing a personal identity.[469] In the context of genomic enhancements, he made distinctions between what is 'grown' (natural) and what is 'made' (genetically enhanced).[470] The former allows for natural identity formation, whereas the latter imposes a technically engineered existence.[471] He thus imagined that genomic interventions could disrupt natural identity formation and invoke beliefs that one's identity has been pre-designed by others.[472]

This aligns with Feinberg's concept of anticipatory autonomy, particularly the *right to an open future*, which is grounded in liberal traditions of personal freedom.[473] Some scholars

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[461] Almeida & Ranisch op cit note 378 at 9.
[462] Ibid.
[463] Ibid.
[464] Ibid.
[465] Ibid.
[466] Cited in Almeida & Ranisch op cit note 378 at 9.
[467] Ibid.
[468] Cited in JE Rueda 'From self-determination to offspring determination? Reproductive autonomy, procrustean parenting, and genetic enhancement' (2021) at 9 available at https://doi.org/10.1111/theo.12349, accessed on 06/11/2024.
[469] Ibid.
[470] Ibid at 9.
[471] Ibid at 9.
[472] Rueda op cit note 468 at 9.
[473] Almeida & Ranisch op cit note 378 at 9.

have applied this principle to genetic modifications, emphasising that such interventions should not constrain a future individual's capacity to define and pursue their own conception of a good life.[474] The preservation of this right is essential to ensuring that prospective individuals retain the ability to make self-determined choices rather than being subject to predetermined genetic conditions.[475] This is reinforced by *procedural* conceptions of autonomy, where it is characterised as a higher-level capacity that allows individuals to evaluate and align their preferences and actions with their personal values and long-term plans.[476] Building on these perspectives, Buchanan et al proposes that genetic interventions should instead aim to expand, rather than limit an individual's life opportunities by providing a form of 'all-purpose goods'[477] While this may be desirable, he acknowledges that it may be complex to determine traits which universally broaden life paths, without inadvertently restricting others.[478]

On the other hand, Massey explains that segments of society believe in prenatal autonomy, whereby parents share the belief that they have the right to decide their children's fates, as the choices of parents historically influence the development of children, such as enrolling children into sports to make them stronger or enlisting the services of private tutors to assist in intellectual developments.[479] However, Massey rejects this belief and proposes that parents should not be able to decide the cosmetic features of their child merely because of prenatal autonomy.[480] Similarly, other scholars have contended that such genomic interventions constituted an excessive measure of parental control, with particular emphasis on the irreversibility of the genetically induced changes.[481] For Fukuyama, this was similar to a 'genetic tattoo', which the future child is not able to remove nor escape.[482] In a similar vein, Habermas warned against the 'irreversible intentions of a third party' which may hinder the freedom and individuality of the prospective child.[483]

Almeida and Ranisch also drew distinctions between what would be perceived as therapeutic and non-therapeutic HHGE applications, asserting that the former may justify certain limitations to future autonomy due to the medical benefits it offers to prospective

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[474] Ibid at 9.
[475] Ibid.
[476] Rueda op cit note 468 at 19.
[477] Almeida & Ranisch op cit note 378 at 9.
[478] Ibid.
[479] Massey op cit note 405 at 6–7.
[480] Ibid at 7.
[481] Almeida & Ranisch op cit note 378 at 9; Rueda op cit note 468 at 19.
[482] Rueda ibid at 7.
[483] Ibid at 9.

children.[484] In some instances, scholars like Gyngell et al have posited that therapeutic genome editing applications could actually enhance a child's autonomy (if proven safe and effective) by removing diseases that would otherwise severely constrain their life choices.[485]

### *Human Dignity and Integrity*

Almedia and Ranisch question the morality of HHGE, in terms of the dignity and integrity of human embryos, by referring to the Universal Declaration on the Human Genome and Human Rights (UDHDHR), which states that "the human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity".[486] The aforementioned statement is used to argue that HGE-manipulated descendants will have had their genetic dignity compromised, without their consent.[487]

## VI METHODOLOGY

The theoretical part of this dissertation will be constructed through desktop research, where the relevant primary and secondary sources (electronic and printed format) will be examined for pertinent information. In practical application of the theory, the transcripts will be analysed using a thematic analysis to examine the semantic and latent content, through inductive and deductive coding.

## VII CHAPTER BREAKDOWN

### Chapter 1: Introduction

The following chapter leads the research topic by introducing key terminology and providing a background on the subject of the deliberative study, namely, HHGE and the potential benefits and issues orbiting the use of CRISPR-Cas9 technology. In addition, it highlights the role of public opinion in regulating said technology, through the DPE technique, and the significance of post-deliberative analyses in extracting a material outcome for policymakers. Furthermore, it provides theoretical insight into previously applied methods of deliberation data analysis, as well as their potential limitations and viability in synthesising such data. Thereafter, framing the significance of the dissertation by providing the relevant research questions, aims and objectives of the research.

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[484] Almeida & Ranisch op cit note 378 at 9.
[485] Ibid.
[486] Ibid at 8.
[487] Ibid.

### Chapter 2: Deliberative democracy and South Africa

This chapter explores the rationale for adopting the DPE tool in the study, emphasising its alignment with South Africa's constitutional culture and participatory democracy. It begins by revisiting the theoretical foundations of deliberative democracy, tracing its origins from ancient Greek democracy to modern conceptualisations influenced by thinkers like Jürgen Habermas and John Rawls. The discussion then examines the relationship between deliberative and participatory democracy, identifying their key similarities, distinctions and areas of compatibility, as well as their significance within the South African participatory democratic framework.

### Chapter 3: Data analysis methodology

This chapter outlines the thematic data analysis methodology applied in the study, including the various stages of the analysis and limitations.

### Chapter 4: Results

After conducting the thematic analysis of the data, this chapter provides the principal themes identified from the data.

### Chapter 5: Summary of findings and Conclusion

In concluding the research, this chapter summarises the findings of the study, provides answers to the research questions raised in Chapter 1, and outlines the study's limitations and future scope.

# *CHAPTER 2*

# *DELIBERATIVE DEMOCRACY AND SOUTH AFRICA*

## I INTRODUCTION

The advent of novel and advanced technologies that require specialised knowledge necessitate the implementation of improved participatory measures or more advanced infrastructures that surpass conventional methods of civic engagement.[488] As such, this study has selected the DPE tool to address the intricacies associated with HHGE or the use of gene editing technologies which raise complex policy decisions.

Embedded within theories of deliberative democracy, DPE emerges as a unique approach to public engagement, drawing its distinctiveness from such theoretical foundation.[489] Thus, in order to gain a comprehensive understanding of this approach, it becomes essential to revisit these theoretical foundations. The previous chapter had introduced the concept of *deliberative democracy*, exploring its potential roots in ancient Greek democracy, building on the ideas of earlier philosophers such as Jurgën Habermas and John Rawls, who were substantial in shaping later versions of the concept, or *modern deliberative democracy*.[490] Furthermore, it discussed the imperative for incorporating deliberative mechanisms into decision-making processes in South Africa, to attain heightened legitimacy in complex policy decisions, augmenting the role of participatory democracy.[491]

The following chapter aims to elucidate the rationale for, or the motivations driving the adoption of the DPE technique in the study, on the basis that it is well-aligned with South African constitutional culture or participatory democracy. It argues that this alignment positions the study as a valuable resource for policymakers, providing evidence-based research for the future regulation of HHGE. Accordingly, to enhance the breadth of the discussion, this chapter will define the concept of deliberative democracy within the context of its historical foundations. Moreover, it will illustrate the relationship between deliberative democracy and participatory democracy, highlighting their essential similarities, differences and potential

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[488] Thaldar et al op cit note 92 at 5.

[489] Effective Health Care Program 'Public Deliberation to Elicit Input on Health Topics: Findings From a Literature Review' (2013) *Agency for Healthcare Research and Quality* 1–198 at 16.

[490] Thaldar et al op cit note 92.

[491] Townsend op cit note 125 at 5.

compatibility. Lastly, it will examine the South African participatory democratic framework to establish how DPE aligns with its principles.

This chapter is structured into three sections, namely, (i) Deliberative democracy: The historical origins; (ii) From participatory to deliberative democracy; (iii) Deliberative democracy: South Africa.

## II DELIBERATIVE DEMOCRACY: THE HISTORICAL ORIGINS

The historical progression of *deliberative democracy* did not follow a linear path, but had developed gradually through the refinement, alteration and reinterpretation of various conceptual components from the historic age to the contemporary world.[492] It may be described as a complex endeavour, followed by the interaction of various individual schools of thought over time, giving rise to its theoretical framework.[493] Despite its manifestation in numerous forms, deliberative democracy is a political theory that centralises on *public reason* and the *justification* of political decisions, to ensure political legitimacy. [494] Legitimate decisions are those based on reasoning that is universally acceptable, or not reasonably susceptible to rejection, thus highlighting the role of public reason.[495] Moreover, it is considered a model for enhancing citizens' influence in political processes, requiring open and unrestricted public discourse among individuals who possess equal rights and standing as citizens.[496] However, it requires that citizens surpass their self-interests and prioritise the overall well-being and interests of all those affected in the political process.[497] In this way, *political justification* is attained.[498] Thus, since the inception of the deliberative paradigm, there has been resistance to preference aggregation (associated with voting procedure), and movement towards a *consensus* premised on justifiable reasoning, or reasoning aligned with the common good.[499] For a more concise elucidation of deliberative democracy, Gutmann and Thompson define it as:[500]

> '[A] form of government in which free and equal citizens (and their representatives), justify decisions in a process in which they give one another reasons that are mutually acceptable and generally accessible, with the aim of reaching conclusions that are binding in the present on all citizens but open to challenge in the future.'

The work of Jane Mansbridge was instrumental in shaping modern deliberative democratic theory, and is often cited for presenting the notion of a *deliberative system*.[501] She

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[492] A Floridia 'The Origins of the Deliberative Turn' 1–21 in A Bächtiger et al (eds) *The Oxford Handbook of Deliberative Democracy* Oxford University Press, (2018) 1–948 at 1.

[493] Ibid.

[494] J Bohman 'Survey article: The coming of age of deliberative democracy' (1998) 6(4) *Journal of Political Philosophy* 400–425 at 401– 402.

[495] Ibid.

[496] Ibid at 402.

[497] Ibid.

[498] Ibid.

[499] Ibid.

[500] Effective Health Care Program op cit note 489 at 16.

[501] See J Mansbridge *Beyond Adversary Democracy* Chicago, IL: University of Chicago Press, (1983), as cited in Floridia op cit note 492 at 3.

did not make direct use of the term *deliberative democracy,* but her idea to deconstruct the downfall of participatory democracy in the early eighties using empirical research, had marked an epoch of novel thinking, which would later influence the foundational elements of modern deliberative theory.[502] This was known as the 'transitional phase'.[503] Significantly, Mansbridge distinguished between aggregative and transformative mechanisms in democratic decision-making, and emphasised that the former involved the quantifying of individual preferences to discern a majority standpoint, while the latter entails deliberating on these preferences with the objective of reaching a consensus.[504] She highlighted that whilst these mechanisms provide distinct approaches in decision-making, neither holds superiority over the other, and are both democratic in nature.[505] The distinction lies in the types of interests involved and the presence of conflicting or shared frameworks within them.[506] Thus, Mansbridge may have not used the term *deliberative democracy,* but she laid the foundation for key principles that would later form the basis of its emerging theoretical framework.[507]

The earliest modern use of the term *deliberative democracy* can be found in the seminal work of an American scholar, Joseph M. Bessette, in his publication *Deliberative Democracy: the Majority Principle in Republican Government* dating back to 1980, where he focused solely on the subject.[508] While Bessette is credited as the first to feature the term *deliberative democracy,* its development involved several influential contemporary philosophers in American law and ambassadors of constitutionalism.[509] Particularly, the contributions of Cass Sunstein, Frank Michelman and Bruce Ackerman were substantial in enriching the concept further, within the context of American political thought and constitutional interpretation.[510]

Consequently, the concept of *deliberative democracy* emerged from a lively debate on how the American Constitution ought to be interpreted, and the form of democracy envisioned by the Founding Fathers, i.e., whether they were primarily influenced by Lockean liberal tradition or civic republicanism.[511] However, an exhaustive examination of the contemporary

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[502] Ibid at 3–4.
[503] Ibid at 3.
[504] Mansbridge op cit note 501, as cited in ibid at 4.
[505] Floridia op cit note 492 at 3.
[506] Ibid.
[507] Ibid at 4.
[508] EI Ani 'Africa and the prospects of deliberative democracy' (2013) 32(3) *South African Journal of Philosophy* 207–219 at 210.
[509] Floridia op cit note 492 at 4.
[510] Ibid.
[511] Ibid.

era isn't imperative. Therefore, I've presented a table below that specifically highlights the emergence of the deliberative field in five distinct stages:[512]

*Table 1.1 The evolution of deliberative democracy in the contemporary era*

| Phase | Description |
|---|---|
| 1) Transition and theoretical innovation | This period was characterised by a notable transition and theoretical progress, as a result of revaluations of the waning models of participatory democracy, coupled with the emergence of the 'deliberative turn'.[513] This was exemplified by the significant contributions of Jane Mansbridge (1980).[514] |
| 2) First formulations and insights | During the early 1980s, a fresh intellectual movement gained momentum, particularly among American academics.[515] This movement centered on the examination of US governmental frameworks and the US Constitution, as the foundation for developing initial deliberative concepts.[516] Key insights stemming from prominent personalities such as Bessette, Sunstein, Michelman, and Ackerman, as mentioned before.[517] |
| 3) Constituent phase | The late eighties witnessed the proper establishment of the deliberative model through published foundational works by Elster (1986), Manin (1987), and Cohen (1989).[518] The theoretical model of deliberative democracy began to establish its boundaries, in referring to alternative paradigms and perspectives that were emerging in contrast to it.[519] |
| 4) Articulation of deliberative field and | In the early nineties, the deliberative model became a clearer and more defined field, influenced by political theory and political science, with key contributions from figures like James Fishkin (1991) and John Dryzek (1990).[520] It also gained prominence in other fields, including policy analysis and planning.[521] |

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[512] Ibid at 2.
[513] Ibid at 2, 3.
[514] Ibid.
[515] Ibid at 2.
[516] Ibid.
[517] Ibid.
[518] Ibid.
[519] Ibid.
[520] Ibid.
[521] Ibid.

| | |
|---|---|
| overlapping traditions | |
| 5) Consolidation of philosophical foundations \| | The fundamental philosophical principles of deliberative democracy were consolidated in the early nineties, through the significant contributions of Jürgen Habermas and John Rawls who were pivotal in establishing modern deliberative democratic theory.[522] |

In exploring the roots of deliberative democracy, it becomes evident that while contemporary proponents and scholars of deliberative democracy wielded great influence over its principles, most contemporary ideas draw upon the ancient theoretical origins and the seminal works of earlier philosophical thinkers, to cultivate its fundamental principles.[523] Thus, the following section will undertake an examination of the philosophical bedrock upon which deliberative democracy is built.

### *(a) The philosophical foundations of deliberative democracy*

The earliest version of deliberative democracy is often traced back to ancient Athens, as stated earlier; however, it is worth highlighting that such procedure did not originate exclusively in Athens, but in other ancient civilisations, like Mesopotamia, China, India, and various other regions.[524] However, academics assert that the notion of dialogical practices or deliberative discussion in classical Athens is misrepresented.[525] Deliberation was characterised differently in the ancient times, and had also referred to 'internal reflection', rather than the modern day conception of deliberative dialogue.[526] The presence of almost eight thousand citizens in the Athenian assembly also meant that meaningful group discussion was impractical.[527] Furthermore, the idea that the Athenians had embodied a form of direct democracy has also been challenged, on the basis that only the male population could participate in political decision-making and represent the interests of their households.[528] Thus, leaning more towards

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[522] Ibid.

[523] S Chambers 'The Philosophic Origins of Deliberative Ideals' 1–15 in A Bächtiger et al (eds) *The Oxford Handbook of Deliberative Democracy* Oxford University Press, (2018) 1–948 at 1.

[524] M Brown 'Deliberation and Representation' 1–18 in A Bächtiger et al (eds) *The Oxford Handbook of Deliberative Democracy* Oxford University Press, (2018) 1–948 at 3.

[525] D Cammack Deliberation in Ancient Greek Assemblies (2020) 115(3) *Classical Philology* 486–522 at 486.

[526] Ibid at 487.

[527] Ibid at 489.

[528] A Haddox 'The Athenian representative democracy' (2016) 1(1) *Undergraduate Journal of Political Science* 125–140 at 125.

a representative democratic system.[529] On the other hand, this analysis is based on contemporary knowledge.[530] The Athenians may have not been aware of the discrepancies between their practices and the democratic principles that they meant to uphold.[531] It is, nevertheless, interesting to observe a renewed interest in the Athenian practice of *sortition* in contemporary deliberative practices, considering the use of random selection in deliberative assemblies, mini-publics and deliberative polls.[532] The Athenian system merely appears to be an example of the earliest possible form of deliberative democracy, which evolved over time, taking various forms. However, in order to discover the philosophical underpinnings of this concept, it is important to revisit the ideas of earlier thinkers and philosophical figures, such as Aristotle, Rousseau, Kant, Mill, Dewey, Rawls and Habermas, who are discussed below.[533]

### *(i) Wisdom and virtue*

The works of Plato had limited influence on deliberative democracy theory, and are not referred to as a foundational source.[534] Plato had his reservations about democracy, and did not support the involvement of ordinary lay persons in democratic decision-making. [535] He believed that a political society required *wisdom and virtue* to thrive, qualities that only a few had possessed in society, and not uniformly observed.[536] Aristotle was of a similar view; although, he added that collectively, the *multitude* could develop a degree of wisdom and virtue, potentially surpassing any individual's capabilities[537]. Aristotle's *wisdom of the multitude* has been more influential in deliberative democratic theory than his political philosophy.[538] His idea that the multitude could reach intellectually valid outcomes through collaboration, had illuminated the 'epistemic claims' of deliberative democracy, in its capacity to potentially yield the correct answers.[539] This is in line with the contemporary idea of deliberation producing an informed public, and ultimately informed public opinion.

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[529] Ibid at 126

[530] Ibid at 125.

[531] Ibid at 125.

[532] Chambers op cit note 523 at 2.

[533] Ibid at 1.

[534] Ibid at 2.

[535] Ibid.

[536] Ibid.

[537] Ibid.

[538] Ibid at 3.

[539] Ibid at 2.

### *(ii) The general will*

The Enlightenment era was characterised by the rise of influential ideas, which truly laid the groundwork for deliberative democratic theories.[540] Jean-Jacques Rousseau was particularly significant during this period, or the first generation of deliberation, with his concept of the *general will* influencing great minds like Rawls and Joshua Cohen.[541]

Cohen's understanding of the *general will* and its production drew heavily on the ideas of Rousseau, where he expressed it as: 'public deliberation proceeding among equals visibly guided by reasons of the common good.'[542] The notion of reasons for the greater good entails a moral responsibility on the intellectual substance of reasoning, to harmonise with solutions and policy outcomes that serve the collective welfare of everyone.[543] Rousseau advocated for a more equal and just society, and emphasised that political decisions should reflect the common interests of the entire community rather than individual or group preferences.[544] He warned against possible divisions that could occur when individual or group preferences are pursued in deliberations, potentially compromising the well-being of the general public.[545] This has triggered discussion about whether deliberation ought to focus solely on the *common good* or if *impartiality* is also a necessary factor.[546]

However, models of deliberative democracy that embrace diversity and healthy debate have departed from Rousseau's *general will,* yet his idea of the equal participation of all citizens (to prevent the undue concentration of power) in decision-making to ensure political legitimacy, remains a fundamental element in all deliberative democratic theories.[547]

### *(iii) Respect: The use of public reasoning*

The use of *public reasoning* originates in the writings of an acclaimed 18th-century German philosopher, Immanuel Kant, who profoundly influenced deliberative theory during the Enlightenment period.[548] His ideas have shaped the way we think about the role of reason in decision-making processes.[549]

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[540] Ibid at 3.
[541] Ibid.
[542] Ibid.
[543] Ibid.
[544] Ibid.
[545] Ibid.
[546] Ibid at 3, 4
[547] Ibid at 4.
[548] Ibid.
[549] Ibid.

While Kant may not have been a proponent of pure democracy and harboured reservations about the (intellectual and political) capacities of ordinary citizens in political decision-making, his commitment to philosophical egalitarianism resonated with democratic ideals.[550] Particularly, his belief that every human being was entitled to *respect,* inspired two central tenets in deliberative democracy theory.[551] Firstly, providing reasons or engaging in reasoned discourse means regarding one's conversational partner as worthy of respect.[552] Moreover, as free, equal and capable of rational thought.[553] Secondly, the argument that the standard of legitimacy in decision-making should rest on hypothetical consent, instead of consent obtained through a voting procedure, or actual consent.[554]

Kant believed that the legitimacy of the law should hinge on the consent of all citizens, prompting him to develop a hypothetical reasons-based legitimacy test: 'If a public law is so constituted that a whole people could not possibly give its consent to it... it is unjust.'[555] Kant is, however, not referring to actual consent, but hypothetical consent established through reasoning and argumentation.[556] As such, the criteria for assessing the legitimacy of policy outcomes are based on whether it can be approved by all citizens in the public sector, attained through argumentation, reasoning and justification.[557] This correlates with Rousseau's perspective on the content of reasoning, grounded in collective welfare.[558] However, unlike Rousseau, who aimed for consensus by avoiding disagreements, Kant believed that engaging in argumentation and criticism was essential in the pursuit of knowledge and truth.[559] Whilst Rousseau avoided contentious discussions, Kant embraced the conflicts that arose from different perspectives.[560] Furthermore, his notion of 'public use of reason', involving a departure from reasoning influenced by personal or group interests (private reason), bears resemblance to Rousseau's version of reasoning based on the common good.[561] Nonetheless, Kant distinguishes his approach by detaching the notion of the common good from specific groups, and instead seeking it within the domain of universal reason.[562]

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[550] Ibid.
[551] Ibid.
[552] Ibid.
[553] Ibid.
[554] Ibid.
[555] Ibid.
[556] Ibid.
[557] Ibid.
[558] Ibid at 5.
[559] Ibid.
[560] Ibid.
[561] Ibid.
[562] Ibid.

Kant also stressed the importance of *autonomy* in moral decision-making.[563] Central to his philosophical narrative is the idea that the exchange of reasons among individuals signifies respect for their individual autonomies (or their ability to govern themselves).[564] In his opinion, these individuals are deserving of respect 'as persons with the same right to their choices and actions as we have to our own.'[565] He famously stated that one should always treat others as ends in themselves rather than as means to an end.[566] This principle highlights the significance of respecting others' autonomy and treating them as rational beings capable of making their own decisions.[567]

He also expressed strong views on freedom from coercion, advocating for self-governance.[568] Self-imposed laws allow one to be both free and governed simultaneously.[569] For him, self-governance refers to being governed by reason.[570] However, to give effect to such reasoning, it is imperative to have freedom of speech, or the ability to voice concerns without restraint.[571] He made a clear distinction between reason and persuasion, on the one hand, and coercion and force, on the other, highlighting that reason operates through persuasion rather than force.[572] This standpoint coincides with Habermas's widely recognised conception of the 'unforced force of the better argument'.[573] Thus, to ensure compelling and legitimate governance, freedom to reason and persuade is essential.[574] Through the use of reason, those in power may be held accountable by justifying their demands to the citizenry.[575] However, it necessitates an active citizenry that is able to perform this role.[576] More so, this method of accountability has only managed to influence 'macro-level' deliberative theories (deliberation is perceived as encompassing an entire system).[577] Nevertheless, Kant's foundational idea that providing reasoning conveys a type of respect is a common thread that has left a lasting imprint on all theories of deliberative democracy.[578]

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[563] Ibid.
[564] Ibid.
[565] L Campbell 'Kant, autonomy and bioethics' (2017) 3(3) *Ethics, Medicine and Public Health* 381–392 at 7.
[566] Ibid at 8.
[567] Ibid.
[568] Chambers op cit note 523 at 4.
[569] Ibid.
[570] Campbell op cit note 565 at 12.
[571] Chambers op cit note 523 at 5.
[572] Ibid.
[573] Ibid.
[574] Ibid.
[575] Ibid.
[576] Ibid.
[577] Ibid.
[578] Ibid.

### *(iv) Governance through discussion*

John Stuart Mill emerged as a prominent philosopher in deliberative democratic theory within the nineteenth century.[579] He gained recognition for his proposition of a *government by discussion,* wherein he embraced the importance of discourse and discussion within a parliamentary setting.[580] In his publication, *On Liberty,* he asserted that freedom of expression (or the liberty to speak freely, debate or critique) within a public space inherently facilitates the uncovering of truth.[581] Thus, similar to Kant, he endorsed the notion of the unrestrained liberty to speak and the protection of this privilege.[582] Akin to Aristotle, he recognised the intellectual advantages of converging diverse viewpoints in an intense debate.[583] This may be the only clear indication of his direct affiliation with deliberative democratic theory, as it is often unclear as to whether he concurred with the system of deliberative democracy, particularly the inclusion of ordinary lay voices in decision-making, being an epistemic elitist.[584]

Mill's concept of *governance through discussion* is found in his work *On Representative Government*, where his idea of representative government envisions a platform for dialogue and discussion, to voice the concerns of the broader populace as its core function.[585] As such, he perceives parliament as 'a place where every interest and shade of opinion in the country can have its cause even passionately pleaded, in the face of the government and of all other interests and opinions, can compel them to listen.'[586] However, peculiarly, he believed that said discussions were not binding on the experts or legislatures who passed the laws, but merely advisory in nature.[587] In his words, 'it is not useful, but hurtful, that the constitution of the country should declare ignorance to be entitled to as much political power as knowledge,' thus it is explicit that Mill may have not supported the inclusion ordinary lay persons in democratic decision-making, or the concept of mini-publics or citizen juries.[588] Conversely, Mill did not deny that these discussions could foster learning, or the education of ordinary citizens, as he did view them as educable. [589] More so, as a dedicated egalitarian democrat, he advocated for the equal representation of everyone's interests in parliamentary

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[579] Ibid at 6.
[580] Ibid.
[581] Ibid.
[582] Ibid.
[583] Ibid.
[584] Ibid.
[585] Ibid.
[586] Ibid.
[587] Ibid.
[588] Ibid.
[589] Ibid.

discussion.[590] However, in his view, not everyone possessed the equal capacity to do so, or to fulfil this role.[591] As such, the direct influence of Mill on deliberative ideologies remains ambiguous.[592]

### *(v) Democratic inquiry*

John Dewey, an influential American philosopher in the twentieth century, is often cited by contemporary theorists and scholars as a precursor to deliberative democracy, to such an extent that he is acclaimed as the 'founding father' of deliberative democratic theory.[593] Rooted in pragmatism, his ideas about democracy, inquiry, and their interconnectedness established the groundwork for what is often referred to as democracy as an inquiry.[594]

He adopted a radical approach in addressing his perceptions of the challenges facing democracy, propelling him towards novel dimensions of democratic thought, which integrated two essential components in democratic decision-making, namely, *deliberation* and *experimentation*.[595] In his famous quote, he contended that 'majority rule, just as majority rule, is as foolish as its critics charge it with. But it never is merely majority rule.'[596] He argued that what is significant is 'the means by which a majority comes to be a majority'.[597] Thus, we should work towards developing 'the conditions and methods of discussion and persuasion,' to make it more rational.[598] Dewey believed that the public was produced by the same methods that created legitimate laws.[599] Accordingly, the orientation towards a more established, compliant and socially structured (organised) method would be useful in attaining valuable knowledge about the 'natural world', and could reform the catastrophe he associated with democracy.[600] This involved the use of scientific method in democratic deliberation, or viewing democracy as a form of *inquiry*.[601]

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[590] Ibid at 6–7.
[591] Ibid at 7.
[592] Ibid at 6.
[593] GF Pappas 'What would John Dewey say about Deliberative Democracy and Democratic Experimentalism?' 57–74 in BE Butler (ed) *Democratic experimentalism* Rodopi, (2013). Vol 9, 1–301 at 57.
[594] Chambers op cit note 523 at 7; Bohman op cit note 494.
[595] Pappas op cit note 593 at 57, 58.
[596] Chambers op cit note 523 at 7.
[597] Ibid.
[598] J Bohman 'Democracy as Inquiry, Inquiry as Democratic: Pragmatism, Social Science, and the Cognitive Division of Labor' (1999) 43(2) *American Journal of Political Science* 590–607 at 590; Ibid.
[599] Chambers op cit note 523 at 8.
[600] Bohman op cit note 598 at 593.
[601] Ibid.

According to epistemological theory, humans inherently seek true belief; however, absolute truth is elusive and not instinctive – there is no direct access to, or sources of, true belief.[602] Thus, humans turn to the most effective methods or scientific inquiry to attain such beliefs, or to test their claims.[603] Inquiry is defined within the context of democracy.[604] It encompasses an ongoing process of 'open critical debate and deliberation', with the ability to develop, when confronted with novel issues, evidence and challenges.[605] Thus, true belief is unassailable and remains invulnerable.[606] It is able to endure the scrutiny of inquiry, or withstand the probing of reasoning, evidence and arguments.[607] Pragmatists contend that scientific inquiry is fundamentally democratic,[608] and is thus successful for that reason.[609] Thus, among the various systems of governance, the most capable of approximating scientific inquiry is democracy, and with this capacity, it is able to generate the most optimal policy decisions.[610] Accordingly, citizens within a democratic society should engage in thoughtful deliberation, by placing their assertions, principles and policy suggestions under the microscope of debate, reasoning and justification, being proficient 'inquirers' within a democratic framework.[611]

Dewey did not support the conceptions of intelligence affiliated with aggregative methods of democracy, or the assumption that intelligence had originated and functioned solely at an individual level, ideally expanded (enlarged) by public discussion.[612] Therefore, even though he endorsed the deliberative technique, he was opposed to the idea that discussion or unrestricted public debate alone could resolve the democracy crisis within an individualist framework.[613] Moreover, although it had the potential to reveal marginalised interests and disseminate new ideas, he believed that said discussions often resulted in conflicting viewpoints, due to disorganised discourse.[614] Consequently, they fell short of delivering the desired outcomes required to govern contemporary complex societies, or what he referred to

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[602] Chambers op cit note 523 at 7.
[603] Ibid.
[604] Ibid.
[605] Ibid at 7, 8.
[606] Ibid at 7.
[607] Ibid.
[608] Scientific inquiry is democratic in three ways: 'it is a collective, communal, and public process; inclusion is an important condition of success because one wants every possible objection to be raised and answered; and it requires broad freedoms for all inquirers', see in Chambers op cit note 523 at 7.
[609] Bohman op cit note 598 at 591.
[610] Chambers op cit note 523 at 7.
[611] Ibid.
[612] Bohman op cit note 598 at 593.
[613] Ibid.
[614] Ibid.

as ‘comprehensive and far-reaching plans.’[615] According to him, these outcomes were only attainable by combining deliberation with scientific inquiry.[616] Unlike Aristotle, who emphasised the *individual* capacities of participants to distribute knowledge in deliberative discussions (in his notion of the wisdom of the multitude), Dewey focused on the methods and procedures that could enhance or optimise the conditions for disseminating knowledge, or effective democratic inquiry.[617]

The works of John Dewey are often sought for a politically and normatively richer version of democracy as a form of inquiry, in contrast to a pure epistemic approach.[618] Illustratively, adopting an epistemic stance suggests that each individual should have the opportunity to voice his/her opinion, because it could improve the outcome of the deliberation.[619] Conversely, from a more normative perspective, it can be argued that each individual possesses the right to voice his/her opinion.[620] This aligns with the moral arguments advanced by Kant and Rousseau, emphasising that everyone should be viewed as equals.[621] However, inspired by pragmatist ideologies, Dewey was predominantly concerned with the outcome of deliberation, which, in his belief, manifested a form of ‘self-reflection’.[622] It had informed as much as it produced a public.[623] Thus, in his support for public discourse and deliberation, Dewey did not emphasise the mere transmission of individual preferences to policymakers, but rather its capacity to produce a public by identifying common interests and shared challenges that could be addressed collectively.[624]

Contrary to Plato’s argument about the intellectual capabilities of the collective and his scepticism regarding their capacity to make rational judgments, Dewey contends that this may be due to ‘structural factors’ that obstruct knowledge dissemination.[625] As such, the most effective methods of scientific inquiry have proven that disseminating knowledge through public debate enhances knowledge.[626]

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[615] Ibid.
[616] Ibid.
[617] Chambers op cit note 523 at 8.
[618] Ibid.
[619] Ibid.
[620] Ibid.
[621] Ibid.
[622] Ibid.
[623] Ibid.
[624] Ibid.
[625] Ibid.
[626] Ibid.

Thus, John Dewey was instrumental in his idea that deliberative democracy should not only consist of the freedom to argue or engage in public discussion, but it should also include a structured communal discussion to determine the most optimal route to consensus.[627]

### *(vi) Rawls and Habermas*

Deliberative democracy, as a theoretical framework, has been dramatically shaped by the contributions of influential thinkers, as discussed above. Among these, Jürgen Habermas and John Rawls stand as pivotal figures, often regarded as the 'inspiring fathers' of deliberative democracy.[628] Their contributions have restructured the landscape of liberal theory, offering a new approach that emphasises the role of public justification, legitimacy and the intertwining of reason and democratic participation.[629]

Their engagement with the concept of deliberative democracy did not follow a linear path, and their contributions were both implicit, explicit and unique.[630] However, it is essential to acknowledge that Habermas and Rawls were not the sole architects of deliberative democracy.[631] Their ideas were drawn into the discourse of deliberative democracy through their philosophical projects and provided a framework that other scholars expanded upon (often in innovative ways), or explicitly rejected in favour of alternative visions of deliberative democracy.[632] Moreover, their involvement during the initial stages of deliberative democratic theory was less visible and more behind the scenes.[633] However, their contributions extended beyond the boundaries of their individual projects, enriching the conceptual and philosophical foundations of contemporary deliberative democracy.[634] While their approaches differ in certain aspects, the philosophical ideas of Rawls and Habermas have had a profound impact on the conceptualisation of deliberative democracy and its central tenets. The previous chapter had already introduced these luminaries and their core principles. As a result, this section does not extensively address said principles, but instead illuminates additional concepts that have also influenced deliberative democracy.

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[627] Bohman op cit note 598 at 590.
[628] Floridia op cit note 492 at 13.
[629] Chambers op cit note 523 at 9, 10, 11, 12.
[630] Floridia op cit note 492 at 13.
[631] Ibid at 15.
[632] Ibid at 13, 15.
[633] Ibid.
[634] Ibid at 13–14.

*(vii) Public justification and public reason*

This new dimension of liberal theory was marked by a shift towards public justification as a cornerstone of legitimacy.[635] Traditionally, the notion of legitimacy focused on obtaining consent (from citizens) and establishing a social contract, as seen in Locke's theory.[636] However, this paradigm has been revolutionised by propounding the idea that legitimacy is achieved through public justification.[637] According to Rawls, 'public justification is not simply valid reasoning, but argument addressed to others'; thus, it requires reasoning for state coercion that garners the approval of all citizens.[638]

The innovative fusion of justification and legitimacy reflects the contemporary emphasis on two key aspects.[639] Firstly, *respect* for the extensive levels of *pluralism* (involving differences and variations in beliefs, values, worldviews and perspectives that exist within a society) inherent in modern societies.[640] Secondly, acknowledgement of the *political autonomy* of every citizen, thus viewing them as *free* and *equal*.[641] As such, one can understand the contemporary conception of deliberative democracy as centring on political justification, meaning that 'the exercise of collective political power is to proceed on the basis of a free public reasoning among equals' to achieve political legitimacy.[642]

Rawls's contribution to deliberative democracy was more straightforward, characterised by his focus on the concept of *public reason*,[643] discussed in chapter 1. In exploring this concept, initially conceived as a fresh perspective to political liberalism, Rawls encountered an unforeseen synergy between public reason and the principles of deliberative democracy.[644] Thus, he found it more suitable within the deliberative democratic context.[645] Accordingly, formulating a novel idea in deliberative democratic theory, Rawls's perception of public reason focused on the type of reasoning that should be reciprocated amongst *equals* in a democratic society.[646]

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[635] Chambers op cit note 523 at 9.
[636] Ibid.
[637] Ibid.
[638] Ibid.
[639] Ibid.
[640] Ibid.
[641] Ibid.
[642] Ibid.
[643] Floridia op cit note 492 at 14.
[644] Ibid.
[645] Ibid.
[646] Chambers op cit note 523 at 9.

Analogous to Rousseau's argument, Rawls was of the view that public reason should be political rather than metaphysical, urging citizens to appeal to shared, non-controversial reasons in democratic discourse.[647] One should not reason from 'unshared ideas of truth, the good life, ultimate values…' that other citizens would not support themselves.[648]

Consequently, for state coercion to be justified and meet the criteria of political legitimacy, it should provide reasoning founded on the interests or concerns of all citizens, or that which could be shared and accepted by all those affected by the decision.[649] In this regard, it is prudent to present arguments based on reasoning that we believe our 'fellow citizens will understand as reasonable'.[650]

The Rawlsian idea of public reason has been supported by only a portion of deliberative democratic theorists, following its particularly narrow approach (the omission of reasoning based on 'comprehensive worldviews', or one's profound convictions of value and truth).[651] On the other hand, numerous normative deliberative democratic theories advocate a more flexible notion of public reason, encouraging deliberants to reason from shared beliefs or the common welfare, thereby avoiding an approach that is excessively constraining.[652]

### *(viii) Habermasian public sphere, ideal speech situation and the unforced force of the better argument*

Jürgen Habermas introduced vital concepts that deeply impacted deliberative democracy, such as 'the public sphere', 'the ideal speech situation', and 'the unforced force of the better argument.'[653] His influence was more complex and implicit than Rawls's.[654] Although he wasn't initially seeking involvement in the deliberative conversation, his theoretical concepts and ideas (within his original works in the seventies) were frequently cited or adapted by various authors of radical democratic ideals, and later utilised to define and consolidate the deliberative field.[655]

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[647] Ibid at 10.
[648] Ibid.
[649] Ibid.
[650] Ibid.
[651] Ibid.
[652] Ibid.
[653] Ibid.
[654] Floridia op cit note 492 at 14.
[655] Ibid.

Habermas presented a distinct political space, positioned between the private domain of the citizen and the public domain of the state, known as the *public sphere*.[656] This unique construct revolved around a novel form of political engagement, where citizens could come together as private citizens, to engage in rational discussion and debate about matters of common interest, or public matters.[657] It was a realm separate from the state, where citizens could freely express their opinions, exchange ideas, and participate in democratic decision-making.[658] Habermas argues that the public sphere is essential for the functioning of democracy, as it allows for the formation of public opinion and holds those in power accountable.[659] In his belief, public opinion goes beyond mere aggregation, in which *genuine opinion* emerges through active involvement in this novel process of political engagement.[660] Thus, it involves opinion that is produced and moulded within the public sphere.[661]

The *public sphere* was viewed as the 'political voice of civil society',[662] which enabled private citizens to make rational judgments on state coercion, and thus, hold state actors accountable, by requiring justification.[663] It is precisely this function of the public sphere, that has exerted a noteworthy influence on deliberative democratic theory.[664]

Habermas's moral theory, or discourse ethics, examined earlier, together with his political theory, are collectively founded on, firstly, his theory of communicative action, and, secondly, his theory of *argumentation*.[665] His theory of communicative action has been discussed sufficiently in chapter 1, thus we will now focus on his linguistic theory of argumentation, which incorporates his concept of *the ideal speech situation*.[666]

The *ideal speech situation* explores the most optimal conditions of argumentation, or creates a hypothetical scenario where individuals engage in rational discourse, free from coercion or domination.[667] It involves participants with equal opportunities to express their views, aimed at achieving consensus.[668] As such, citizens should provide reasons and

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[656] Chambers op cit note 523 at 10.
[657] Ibid at 10, 11.
[658] Ibid at 11.
[659] Ibid.
[660] Ibid.
[661] Ibid.
[662] Ibid at 10.
[663] Ibid at 11.
[664] Ibid.
[665] Ibid.
[666] Ibid.
[667] Ibid at 11, 12.
[668] Ibid.

justification in line with these formal conditions of argument.[669] However, before proceeding to such conditions, it is significant to highlight that this theory does not align with the principles of deliberative democratic theory or political ideologies.[670] Instead, as Habermas emphasises, it functions as a linguistic construct, based on the procedural guidelines of discourse.[671] For instance, it doesn't pertain to the justification of specific *state coercion*, but rather the justification presented to fellow individuals; it emphasises on the procedural regulations that govern the process of argumentation, rather than the fundamental substance of reasoning; furthermore, it is grounded on a theoretical supposition, rather than representing practical objectives achievable in real-life scenarios.[672]

In contrast to Rawls's public reason, which focuses on the scope of reasoning acceptable in political justification, Habermas instead looks at a more structured mode of discourse based on the procedural rules of reasoning.[673] In this framework, justification is 'ultimately based only on reasons that withstand objections under demanding conditions of communication.'[674] Transitioning to such conditions, it is stipulated that '(i) no one can be excluded, (ii) equal opportunity to speak, (iii) no deception or manipulation, (iv) no coercion or external pressure can be brought to bear.'[675] Habermas himself concedes that these conditions are not meant to be an attainable standard in practice, characterising them as 'strong idealizations'.[676] Moreover, he ultimately discontinued the term, due to the widespread interpretation of the ideal speech situation as presenting a normative goal of this nature.[677]

Conversely, the overall view of the aforementioned conditions has had a significant impact on deliberative democracy.[678] This impact cannot be overstated, considering that virtually all deliberation models have incorporated varied forms of these conditions.[679]

It is intriguing to observe that a succinct form of these four conditions have been encapsulated in Habermas's renowned expression: the 'unforced force of the better argument.'[680] This expression denotes the idea that in rational discourse, the strength of an

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[669] Ibid at 11.
[670] Ibid.
[671] Ibid.
[672] Ibid.
[673] Ibid.
[674] Ibid.
[675] Ibid at 12.
[676] Ibid.
[677] Ibid.
[678] Ibid.
[679] Ibid.
[680] Ibid.

argument lies not in its coercive power, but rather in its ability to convince through reasoned persuasion.[681] This emphasises the power of reason in acknowledging the freedom and equality of citizens.[682] Consequently, much like Kant, Habermas stresses that the provision of reason shouldn't occur through coercion or by force, but through a process that upholds an individual's freedom and equality. [683] Thus, at the core of deliberative democracy lies the idea that furnishing reasons not only leads to improved outcomes, but also serves as a method of acknowledging the equal and independent standing of each citizen. [684]

## III FROM PARTICIPATORY TO DELIBERATIVE DEMOCRACY

The decline of the participatory democracy model in the 1980s signified a period of change, in which certain scholarly works aimed to advance the current model and steer it into novel pathways.[685] Precisely, the works of Jane Mansbridge, referred to earlier.[686] However, it is important to emphasise that deliberative democracy did not emerge as the direct successor of participatory democracy.[687] These concepts correspond to different eras and contextual frameworks, culminating in fields of study that would only partially intersect later on.[688] Furthermore, their connection is not well-defined and remains ambiguous.[689] Scholars share differing viewpoints as to whether said concepts share a continuous thread, complement each other, are adjacent but distinct, or if they represent a form of departure.[690] Thus, before examining the South African public participatory model, it is important to first understand the nature of the relationship between deliberative democracy and participatory democracy per se. I argue that although these concepts offer separate approaches and emphasise different aspects, they are not entirely distinctive. They emerge from shared principles, and are potentially complementary. This section will focus on the similarities, differences and possible compatibility of these two concepts.

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[681] Ibid.
[682] Ibid.
[683] Ibid.
[684] Ibid.
[685] Floridia op cit note 492 at 3.
[686] Ibid.
[687] Ibid at 4.
[688] Ibid.
[689] S Elstub 'Deliberative and Participatory Democracy' 1–18 in A Bächtiger et al (eds) *The Oxford Handbook of Deliberative Democracy* Oxford University Press, (2018) 1–948 at 1.
[690] Ibid at 2.

*(a) Participatory democracy*

Participatory democracy had gained prominence in the sixties and seventies as a direct response to the prevailing notions of empirical democratic theory and neo-liberalism, which heavily influenced the study of democracy.[691] The early stages can be traced back to the Port Huron Statement created by the 'Students for a Democratic Society' in 1962, which challenged the assertions of empirical democratic theory.[692] These included ideas of limited capacity and the lack of motivation of ordinary citizens to engage in political decision-making.[693] Furthermore, the notion that citizens did not wield decisive influence in decision-making procedure, and would thus not directly experience the outcomes of their political choices.[694] On the contrary, participatory democracy theorists posit that this supposed lack of motivation and capacity was as a result of socio-economic inequalities and rational barriers which hinder effective participation.[695] They contend that under appropriate conditions, or the provision of reasonable opportunities and incentives for participation, citizens would become better informed, and could possess the willingness and necessary skills to actively engage in democratic processes.[696] As such, central to the conceptions of participatory democracy is the *participation* element, or the involvement of citizens in political practice.[697] Given this rationale, political participation should not only be found in the state, but there ought to exist a multitude of opportunities for citizens to engage in political involvement, such as within their workplaces, communities and the media.[698]

Participatory democracy rests upon three primary justifications.[699] The first justification speaks of its ability to embody the true essence of democracy, by offering a 'more authentic and normatively strident' view of democracy, compared to liberal representative versions.[700] Thus, by enabling each citizen to collectively decide on matters that impact them, in any form of domain (political, economic, social), it elevates both political and individual autonomy, aligning with democratic ideals of a government by the people.[701] Moreover, increased citizen

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[691] D Vitale 'Between deliberative and participatory democracy: A contribution on Habermas' (2006) 32(6) *Philosophy & social criticism* 739–766 at 749; ibid.
[692] Elstub op cit note 689 at 2.
[693] Ibid.
[694] Ibid.
[695] Ibid at 3.
[696] Ibid.
[697] Vitale op cit note 691 at 749.
[698] Elstub op cit note 689 at 3.
[699] Ibid at 4.
[700] Ibid.
[701] Ibid.

participation can foster trust and broader public support of political institutions.[702] Secondly, heightened participation could alleviate social-economic inequalities, prompting a more substantive democracy, through political equality and the inclusion of everyone in political decisions.[703] Thirdly and lastly, the educative role of increased political participation, in which citizens may become better informed and more socially aware.[704]

The objective of the participatory model was not to supplant representative democracy, but to establish modes of direct democracy that explore different avenues of discussion and political deliberation, in harmony with the representative framework.[705] In this way, it aims to eradicate or at least mitigate issues of legitimacy present in representative frameworks, allowing for greater transparency, openness, as well as accountability in governmental practices.[706] As such, the element of participation necessitates a form of communication and dialogic procedure to actualise this goal of legitimacy.[707] This is because participation is perceived as 'a dynamic act of imagination, that requires participants to change how they see the world.'[708] Consequently, it requires a kind of intersubjective relation envisioned by Habermas, which can only be acquired through public dialogue.[709] This notion is further endorsed by a notable participatory democracy theorist, Carol Pateman, who believes that 'the theory of participatory democracy is built around the central assertion that individuals and their institutions cannot be considered in isolation from one another.'[710] Furthermore, in referring to the third justification of participatory democracy, the public may only become better informed if exposed to differing arguments or deliberative discussion, and not mere voting.[711] Thus, communication and dialogic procedure are essential features in participatory practices. Given the aforementioned points, participatory democracy can be interpreted as a model that aims to enhance and broaden democratic procedure, by democratising different social spaces, and in turn allowing for inclusive citizen engagement in political decision-making.[712] It is guided by

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[702] Ibid.
[703] Ibid.
[704] Ibid.
[705] Vitale op cit note 691 at 750.
[706] Ibid.
[707] Ibid at 751.
[708] Ibid.
[709] Ibid.
[710] C Pateman *Participation and democratic theory* Cambridge University Press, (1970) at 42, as cited in ibid.
[711] Ibid.
[712] Ibid at 752.

collective political will-formation and can be executed directly and indirectly through extensive and decisive public discussions.[713]

### *(b) Deliberative democracy and participatory democracy*

There is significant discord concerning the true nature and relationship between deliberative and participatory democracy, as stressed earlier.[714] However, although distinct in approach, there are certainly parallels between the two concepts, suggesting their potential for mutual enhancement. Thus, it is imperative to explore their potential similarities, differences, and how these concepts may enrich each other, in the discovery of their true relationship.

As a starting point, both participatory and deliberative democracy emphasise and emerge from the challenge of achieving legitimacy in political decision-making.[715] Moreover, they are interconnected in their solution to reintegrate citizens into public discourse and political decision-making, through participation and deliberative engagement.[716] However, they offer distinct approaches in solving this dilemma, due to differing points of focus.[717]

Through a participatory lens, the core element is *participation* itself.[718] It focuses on expanding direct democracy practices by democratising different social spaces, to increase citizen participation, and to ensure that all citizens have an equal enjoyment of their political rights, whilst curtailing socio-economic disparities.[719] Conversely, deliberative theorists highlight the centrality of *deliberation*, placing emphasis on the process of thoughtful discussion and collective will-formation in order to attain consensus.[720] Moreover, they focus on the utilisation of discourse and communication as a form of power, asserting that such practices should be legally institutionalised.[721] However, in similarity, I suggest that both processes, to a greater or lesser degree, require the core elements of *participation* and *deliberation* for effective functionality in a democratic society. This is discussed below.

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[713] Ibid.

[714] Elstub op cit note 689 at 2.

[715] Vitale op cit note 691 at 753.

[716] Ibid.

[717] Ibid.

[718] Ibid.

[719] Ibid.

[720] Ibid.

[721] Ibid.

### *(i) Deliberative democracy and participation*

The element of *participation* is not novel within the context of deliberative democracy and includes two fundamental principles: the involvement of all those affected by the decision and the inclusion of all relevant opinions on the matter.[722] Therefore, the inclusion of all subjects to the decision is crucial, in accordance with the deliberative perspective: 'democracy is a political arrangement that ties the exercise of collective power to reason-giving among those subject to collective decisions.'[723] In Dryzek's foundational explanation of legitimacy in deliberative democracy, he provides that it requires 'reflective assent through participation in authentic deliberation by all those subject to the decision in question.'[724] As such, the condition of 'reflective assent' means that citizens should engage in deliberation themselves in order to provide such assent, and that it cannot be conveyed through elected representatives to be reflective.[725] Thus, the element of direct participation is significant in meeting deliberative legitimacy.[726]

On the contrary, participatory theorists argue that deliberative democrats have contributed poor efforts towards the broadening of participatory opportunities.[727] Furthermore, when interest is displayed, they tend to label them as instances of deliberative democracy.[728] Pateman precisely argues that deliberative democrats have exhibited an obsessive preoccupation with mini-publics as a form of participation.[729] However, despite the fact that mini-publics have garnered significant attention, deliberative democrats have also explored other arenas, including interest groups, workplaces, parliament, social movements, political parties and the mass media.[730] Pateman also critiques the notion of sortition in mini-publics, asserting that each citizen should have the right to participate in deliberations and should not be subjected to random selection.[731] Even though mini-publics are customised to enable effective and high-quality citizen deliberation, her critique entirely disregards the way in which the method of sampling (random selection) is intended to tackle socio-economic barriers that

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[722] Elstub op cit note 689 at 6.

[723] J Cohen 'Reflections on Deliberative Democracy' in T Christiano & J Christman (ed) *Contemporary Debates in Political Philosophy* Oxford: Wiley-Blackwell, (2009) 247–263 at 248 , as cited in ibid.

[724] JS Dryzek *Foundations and Frontiers of Deliberative Governance* Oxford: Oxford University Press, (2010) at 23, as cited in ibid.

[725] Elstub op cit note 689 at 6.

[726] Ibid.

[727] Ibid.

[728] Ibid.

[729] C Pateman 'Participatory Democracy Revisited' (2012) 10(1) *Perspectives on Politics* 7–19 at 10, as cited in ibid.

[730] Elstub op cit note 689 at 6.

[731] Pateman op cit note 729.

arise in political participation.[732] According to Fishkin, said socio-economic barriers make mass deliberation impossible, thus he advocates for a method of sampling that would still ensure that participants mirror the diverse composition of the wider population, and is thus inclusive.[733] Significantly, research has revealed that 'innovative mini-publics genuinely have, from time to time, had major impacts on macro-politics.'[734]

Pateman presents yet another relevant criticism of deliberative democratic theory.[735] She argues that it 'still leaves intact the conventional institutional structures and political meaning of "democracy".'[736] Thus, it fails to adopt the radical changes necessary to create greater opportunities for citizen participation.[737] This encompasses reforming orthodox institutional structures and establishing better social, political, and economic rights that can effectively facilitate participation.[738] In the same breadth, although participatory democrats emphasise the importance of communication and public discourse in citizen engagement (aligning with deliberative ideals), they do not progress beyond this point, or ensure that these processes are safeguarded through legal means.[739] Thus, it is explicit that these concepts have differing points of focus or emphasis.

I argue that even though the element of participation is integral to both participatory and deliberative practices, in which there is a shared need to expand political engagement beyond the confines of traditional voting, these two models take separate paths in determining the appropriate form of participation.[740] They diverge in their perspectives on the specific nature of participation required.[741]

### (ii) *Participatory democracy and deliberation*

Participatory democrats are primarily interested in the scope, breadth and depth of public participation in political decision-making, so that it reflects a form of inclusivity.[742] In contrast, deliberate democrats, although also concerned with inclusivity, emphasise the role of public

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[732] Elstub op cit note 689 at 6.
[733] Fishkin op cit note 326, as cited in Elstub op cit note 689 at 6.
[734] RE Goodin & JS Dryzek 'Deliberative impacts: The macro-political uptake of mini-publics' (2006) 34(2) *Politics & society* 219–244 at 238.
[735] Pateman op cit note 729.
[736] Ibid.
[737] Elstub op cit note 689 at 7.
[738] Ibid.
[739] Vitale op cit note 691 at 754.
[740] Elstub op cit note 689 at 7.
[741] Ibid.
[742] Ibid.

reason and the argumentative structure of public discourse, before deriving a decision.[743] However, participatory democrats themselves have found merit in deliberative methods.[744] Pateman highlights the importance of deliberation in not only participatory democracy, but across all democratic practices.[745] Floridia acknowledges the significance of the 'transitional phase' in the eighties, which diverted the conversation from participatory democracy to deliberative democracy, specifically highlighting the roles of Mansbridge and Barber during this period.[746] Barber emphasised the significance of 'public talk' with the objective of reaching consensus.[747] In his view:[748]

> 'Discourse enables us to explore preferences, comparable scales, and the impact of time and place; it enables us to ascertain our true desires as individuals and as a community...choices are generally more coherent and less paradoxical than the logical dilemmas extrapolated from them, especially if the choices are informed by a process of robust democratic discourse.'

In a similar vein, Mansbridge endorsed decision-making that involved collective reasoning, ultimately leading to mutual agreement 'on the most optimal solution'.[749]

The value of deliberation in participatory democracy has rightly been conceded to, considering its aptitude for enriching the normative and explanatory capacity of said democracy.[750] Scholars claim that participatory democracy without deliberation is merely 'aggregative participatory democracy', with citizens' opinions regarded as external factors.[751] In this sense, I argue that participatory democracy may not be appropriately justified without deliberation. Firstly, it would not be able to fulfil an educative role and produce better informed citizens (according to justification two), without exposure to differing arguments or a form of deliberation.[752] Secondly, the lack of deliberation means that it would not be able to produce authenticity (according to justification one), as it may be challenging to differentiate between authentic and manipulated opinions.[753] Thirdly, deliberation through public reasoning

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[743] Ibid.
[744] Ibid.
[745] Pateman op cit note 729.
[746] A Floridia 'Beyond participatory democracy, towards deliberative democracy: elements of a possible theoretical genealogy' (2014) 44(3) *Rivista italiana di scienza politica* 299–326 at 300, as cited in Elstub op cit note 689 at 8.
[747] Elstub ibid at 8.
[748] Ibid.
[749] Mansbridge op cit note 501 at 3, as cited in ibid at 8.
[750] Elstub ibid at 8.
[751] Ibid.
[752] Ibid.
[753] Ibid.

incorporates an aspect of accountability, in which all citizens, including those in dominant positions (elite class), are required to provide reasoning and justifications for all their requests.[754] In this way, it may minimise socio-economic inequalities (justification three), as it would be difficult for powerful elites to further their self-interests.[755] Additionally, it would create avenues for marginalised societal groups to illuminate said inequalities, with appropriate reasoning.[756] Deliberative democrats have also argued that 'the justifications of political consciousness and the learning processes attendant on participation make sense only in a context of public discussion wherein each individual can think, ponder and have the opportunity to change, either totally or in part, his or her original position as a result of the exchanges.'[757]

Therefore, in light of the above, it can be inferred that not only is deliberation a necessary requirement in participatory practices, but such combination can potentially enrich and strengthen the principles of democracy.[758] However, the question then arises, can these concepts be effectively combined to function together? This is explored in the subsequent section.

### *(c) Deliberative democracy and participatory democracy: Can they be combined?*

The idea of combining deliberative and participatory ideals appears ambitious and may be promising in enhancing political legitimacy and democracy at large.[759] However, it does come with much difficulty, considering their distinct approaches to democracy and differing focal points, discussed earlier.[760]

Scholars contend that participatory democratic theory does not accommodate the complexity in contemporary societies, as is the case with deliberative methods.[761] Moreover, participatory democrats are critiqued for not being cognisant of the relevance of 'expertise' in governing contemporary societies, where the extent of social complexity may be restrictive on its ability to function as both a participatory and deliberative democracy.[762] As a result, to allow for effective and quality deliberation, the level of participation needs to be reduced.[763] Steiner

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[754] Ibid.
[755] Ibid.
[756] Ibid.
[757] Ibid.
[758] Ibid.
[759] Ibid at 13.
[760] Vitale op cit note 691 at 753.
[761] Elstub op cit note 689 at 9.
[762] Ibid.
[763] Ibid.

believes that an increased amount of participants may lead to decreased motivation and incentive to participate, in some or most participants, ultimately reducing deliberative quality.[764] Furthermore, reduced participation is necessary to shield participants from the pressures and demands of society, which could affect the quality of deliberations.[765] Conversely, although conceding to the complexity criticism, participatory democrats argue that deliberative democrats overly emphasise the aspect of complexity.[766] Thus, some scholars believe that a *participatory deliberative* approach may be impractical, favouring an approach that effectively reconciles the distinctions between the two concepts.[767]

On the contrary, Dryzek argues that in the absence of deliberation, participatory democracy would contribute to the complexity dilemma.[768] Correspondingly, the lack of inclusive participation in deliberation could result in 'self-interested elite dominance'.[769] This may be true; however, I argue based on a study that sought to gauge the deliberative interests of participants, which found that 'actual deliberative participation was less biased and skewed' than voting.[770] Thus, deliberation should not be perceived as the territory of the dominant class.[771] Moreover, the nature of participation is perceived differently across both concepts. From a deliberative stance, inclusive participation doesn't necessarily mean including everyone in the deliberation, as this may be impractical, but ensuring that everyone is descriptively represented through diversity.[772] Hence, random selection becomes vital in producing quality deliberation by alleviating possible socio-economic disparities that may arise.[773]

Another intriguing point raised by deliberative democrats is the degree to which citizens want to be involved in decision-making, and the question of whether citizens genuinely seek the expansion of participatory opportunities.[774] Warren argues that:[775]

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[764] J Steiner *The Foundations of Deliberative Democracy: Empirical Research and Normative Implications* Cambridge: Cambridge University Press, (2012) 1–272 at 32, as cited in ibid.

[765] Elstub op cit note 689 at 9.

[766] Ibid at 10.

[767] Ibid.

[768] JS Dryzek 'Complexity and rationality in public life' (1987) 35(3) *Political Studies* 424–442 at 436, as cited in ibid at 9.

[769] Ibid.

[770] Elstub op cit note 689 at 11.

[771] Ibid.

[772] Ibid at 6.

[773] Ibid.

[774] Ibid at 9.

[775] ME Warren 'What should we expect from more democracy? Radically democratic responses to politics' *Political Theory* (1996) *24*(2) 241–270 at 242, as cited in ibid.

> 'Individuals are likely to find decision-making so burdensome and inefficient that most will withdraw into cynical apathy. This will leave most decisions to an activist few who will, ironically, make decisions based on the authority they derive from a participatory process.'

In provision of empirical evidence, Mansbridge elucidates that citizens are not always willing to participate in deliberation, due to its perceived complexity.[776] The findings of Hibbing and Theiss-Morse corroborate her position.[777] According to their evidence, citizens would prefer not to engage in deliberation.[778] Thus, in formulating a *stealth democracy thesis*, they contend that the level of participation in deliberative processes is contingent on the degree of corruption within a representative democratic framework.[779] Citizens become hesitant when corruption is overwhelming, yet they do find a need to rectify this imbalance by contributing their perspectives.[780] However, they would prefer an efficient representative democracy that minimises the need for their active participation.[781] This evidence has been contested by many scholars.[782] Some critics have associated *stealth beliefs* with authoritarianism, asserting that such beliefs harbour authoritarian inclinations and could only be overcome through increased deliberative public engagement attempts, potentially diminishing their prevalence.[783] Steiner asserts that the data is only evidence of 'what Americans say about political talking' and does not provide insight into 'how much they actually talk about politics.'[784] In addition, he remains doubtful that the data actually captures deliberation, but normal talk.[785] However, the most compelling counter-argument has been provided by Neblo et al, based on evidence from a survey-based study.[786] They posit that generating more meaningful avenues for deliberative engagement would indeed spark greater interest in the public.[787] Their findings had indicated a more pronounced inclination for deliberative participation than anticipated.[788] Interestingly, citizens who were most determined to participate, were those who were specifically

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[776] Mansbridge op cit note 501, as cited in Elstub op cit note 689 at 10.

[777] JR Hibbing & E Theiss-Morse *Stealth Democracy: Americans' Beliefs About How Government Should Work* Cambridge: Cambridge University Press, (2002) 1–275, as cited in Elstub op cit note 689 at 10.

[778] Ibid.

[779] Ibid.

[780] Ibid.

[781] Ibid.

[782] Ibid.

[783] P Muhlberger 'Stealth democracy: Authoritarianism and democratic deliberation' (2018) 14(2) *Journal of Deliberative Democracy* 1–38 at 25.

[784] Steiner op cit note 764 at 39, as cited in Elstub op cit note 689 at 10.

[785] Ibid at 40.

[786] MA Neblo et al Who Wants to Deliberate– And Why? (2010) 104(3) *American Political Science Review* 566–583, as cited in Elstub op cit note 689 at 11.

[787] Ibid at 567.

[788] Ibid at 582.

disinterested in 'standard partisan and interest group politics'.[789] The stealth democracy thesis did receive some support; however, significantly, there was substantial evidence in support of the *deliberative thesis.*[790] To illustrate, citizens would be more willing to participate if they perceived the representative system as less corrupt.[791] Additionally, the survey's revelation of a higher interest in 'specifically deliberative opportunities' compared to 'more general political participation' was also particularly fascinating, underscoring the significant potential for future meaningful deliberation.[792]

Conversely, another quantitative study conducted in the US yielded contrasting insights.[793] It was discovered that while deliberation could indeed foster tolerance, exposure to differing viewpoints might also discourage active participation.[794] This phenomenon arises as citizens often choose to evade conflicts to maintain social harmony.[795] As a result, Mutz asserts that participatory and deliberative democracy stand in opposition, essentially lacking compatibility, as they cannot be achieved simultaneously.[796] However, critics have questioned the reliability of this evidence, contending that it may be based on representative surveys.[797] More so, it is unclear as to whether the research pertains to deliberation or daily talk.[798] Citizens may shy away from conflict in informal discussions, but may engage differently if made aware that their input could contribute to a legally binding collective decision.[799]

Furthermore, I argue that the evidence provided is insufficient in drawing such firm conclusions, precisely in reference to the findings presented by Neblo et al.[800] According to their evidence, even though 60% of the participants expressed a preference for conflict avoidance, they still displayed interest in deliberating with members of Congress.[801] Hence, in the context of deliberative participation, conflict avoidance may not necessarily dictate outcomes.[802] It is crucial to note that while conflict avoidance did have some influence in the

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[789] Ibid.
[790] Ibid at 570.
[791] Ibid.
[792] Ibid.
[793] Elstub op cit note 689 at 12.
[794] Ibid.
[795] Ibid.
[796] DC Mutz *Hearing the Other Side: Deliberative Versus Participatory Democracy* Cambridge: Cambridge University Press, (2006) at 2, 131, as cited in ibid at 11.
[797] Elstub op cit note 689 at 12.
[798] Ibid.
[799] Ibid.
[800] M Neblo, et al 'Who Wants to Deliberate–and Why?' (2009) *American Political Science Review* 1–43.
[801] Ibid at 33.
[802] Ibid.

study, the citizens' primary concern was their limited understanding of the subject matter.[803] This is precisely a challenge that deliberative participation aims to address.[804]

In essence, the notion of integrating deliberative democracy with participatory democracy holds the potential to enhance political legitimacy and overall democratic functioning.[805] However, this ambitious undertaking is not without challenges, given the distinct approaches offered by these concepts and their divergent points of emphasis, as discussed above. Conversely, despite their fundamental differences, the evidence opposing their compatibility remains inconclusive and does not detract from their potential to collectively enhance the role of democracy in society.[806] However, even though their combination is desirable, this study did not advocate for this position due to the intricacies discussed above. Moreover, a purely deliberative approach was deemed more appropriate for the study in light of the nature of the policy decisions.

## IV DELIBERATIVE DEMOCRACY: SOUTH AFRICA

Public participation in the law-making process is a constitutionally entrenched right within the South African legal framework, deemed the cornerstone of its novel constitutional democracy.[807] In light of a rich history of racial discrimination and gross inequality within its apartheid regime, precisely the exclusion of certain citizens from law-making processes,[808] South Africa has made significant strides in securing public involvement in policy formulations, reflecting the country's commitment to inclusivity, transparency and accountability in governmental procedure.[809] This imposes a moral and legal duty on all organs of state to facilitate the active involvement of citizens in policy formulation, upholding the values of its constitutional democracy.[810] In *Doctors for Life International v Speaker of the National Assembly*,[811] the Constitutional Court, in considering the country's rather fragmented past of apartheid, held that 'merely to allow public participation in the law-making process is,

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[803] MA Neblo *Deliberative Democracy Between Theory and Practice* Cambridge: Cambridge University Press, (2015) 1–211 at 149, as cited in Elstub op cit note 689 at 12.
[804] Elstub op cit note 689 at 12.
[805] Ibid at 13.
[806] Ibid.
[807] N Maphazi et al 'Public participation: a South African local government perspective' (2013) 6(2) *African Journal of Public Affairs* 56–67 at 1.
[808] Stuurman op cit note 113 at 309.
[809] Ibid at 331.
[810] Constitution of the Republic of South Africa, 1996.
[811] *Doctors for Life International v Speaker of the National Assembly* 2006 (6) SA 416 (CC).

in the prevailing circumstances, not enough. More is required. Measures need to be taken to facilitate public participation in the law-making process.'[812]

This holds great promise for the prospects of deliberative democracy in South Africa, particularly through the application of the deliberative technique (DPE) to reinforce the fundamental right to public participation, providing greater consolidation to its constitutional democracy. The previous section did not prove the compatibility of deliberative and participatory democracy; however, as demonstrated, these two concepts seek to address similar challenges, emerge from shared principles and could be mutually enriching.

In the South African context, my contention is that the use of the DPE approach, although not expressly, is already well-aligned with the country's legal framework, offering an improved platform for historically marginalised voices to be heard. It corresponds, to a great extent, with the foundational principles embedded in its participatory democracy.

Therefore, in this section, I assess the nature and scope of the right to public participation in South Africa, and how it correlates with DPE goals and objectives, ultimately proving that the DPE technique utilised in the study fits well with the South African constitutional culture, making the study more valuable to policymakers when regulating HHGE in the future.

### *(a) DPE and the nature and scope of the right to public participation*

In order to examine how DPE fits into the South African legal framework, it is important to first revisit the core ideas and objectives of DPE. As covered earlier, DPE represents a participatory approach where ordinary citizens engage in respectful and thoughtful discussion, exchanging diverse perspectives, to collectively reach informed decisions and overall consensus on moral and ethical issues.[813]

Emphasising its significance, the DPE technique is strategically utilised in policy-making, specifically in addressing contentious matters marked by conflicting societal values.[814] These are situations where a lack of trust in government policies could potentially arise.[815] These decisions necessitate the blending of expert technical knowledge with real-world

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[812] Ibid at para 130.
[813] Effective Health Care Program op cit note 489 at 15.
[814] S Solomon & J Abelson 'Why and when should we use public deliberation?' (2012) 42(2) *The Hastings Center Report* 1–5 at 1, 2.
[815] Ibid at 3.

perspectives from the public.[816] As a result, this research gravitates towards the use of DPE precisely for the regulation of HHGE, which satisfies the aforementioned criteria.

At its core, the primary objective of DPE is to generate policy decisions that are deemed legitimate, through their acceptance by the wider public, particularly those who are directly impacted by these decisions.[817] This is obtained through inclusive participation, in which every citizen possesses an equal opportunity to engage and bear influence over the deliberative outcome.[818] In this regard, the aims and objectives of DPE can be described as follows:

(i) Participation and influence: It offers individuals an opportunity to participate and directly influence decisions on crucial matters that impact their lives;[819]
(ii) Enhanced policy outcomes: It generates improved policy decisions by leveraging a comprehensive understanding of public values and priorities;[820]
(iii) Transparency and accountability: It allows for increased transparency, accountability, and thus legitimacy in decision-making processes, by gaining insight into the success or failure of future policy outcomes;[821]
(iv) Empowerment and education: It has the ability to empower, educate, and motivate the public, enabling them to make informed contributions and decisions;[822]
(v) Government-citizen relations: It cultivates improved relationships between the government and citizens, fostering greater public trust in their decisions;[823]
(vi) Mutual respect and recognition of diversity: It establishes a form of mutual respect among participants, who are able to acknowledge the ethnic, cultural and linguistic diversity of other participants.[824]

### *(i) The nature and scope of the right to public participation in South Africa*

In the post-apartheid era, South Africa embarked on a remarkable journey of transformation, aimed at addressing historical inequalities and injustices, following the first democratic election in 1994 and becoming a constitutional democracy thereafter. In *Doctors for Life*,[825]

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[816] Ibid.
[817] E Beauvais & A Baechtiger 'Taking the goals of deliberation seriously: A differentiated view on equality and equity in deliberative designs and processes' (2016) 12(2) *Journal of Public Deliberation* 1–18 at 2.
[818] Ibid.
[819] Warburton op cit note 90 at 12.
[820] Ibid.
[821] Ibid.
[822] Ibid.
[823] Cass op cit note 89.
[824] Ibid; Beauvais op cit note 817 at 2.
[825] *Doctors for Life* op cit note 811.

the court contended that the nature of the South African democracy can only be comprehended through the lens of its history.[826] Thus, we are then able to understand the true nature of the right to participate, as said history provides the backdrop against which these transformative efforts were undertaken. Ngcobo J pointed out:

> 'The nature of our democracy must be understood in the context of our history. As has been observed, during the struggle against apartheid, a system that denied the majority of the people a say in the making of the laws which governed them, the people developed the concept of the people's power as an alternative to the undemocratic system of apartheid. This concept ensured that the people took part in community structures that were set up to fight the system of apartheid. But as has been observed, the significance of these "organs of the people's power" went beyond their intended purpose: "They were also seen as crucial in laying the foundation for the future participatory democracy that [the people] were fighting for and that we are operating under."'[827]

Given this account, South Africa's novel constitutional democracy accentuates *democratic participation*, in order to disintegrate the undemocratic practices of the past, which permeated historic societies.[828] This history informs and shapes the principles and goals of our current democracy, and is responsible for the elevated status granted to the *right to participate*.[829]

The introduction of the novel Constitution in 1996 represented a key initiative in establishing greater opportunities for public participation in the South African legislative process, safeguarding this fundamental right across all spheres of government.[830] To emphasise this commitment, as articulated in its preamble, the Constitution is affirmed as the supreme law of the land, [831] assigned the responsibility to 'lay the foundations for a democratic and open society in which government is based on the will of the people…' The nature of our Constitution was further expounded in *Doctors for Life,*[832] where the Constitutional Court, in referring to its previous judgment in *Minister of Health v New Clicks SA (Pty) Ltd*,[833] held that what our Constitution requires, is a government characterised by openness and transparency, enabling the active participation of the public in the legislative processes conducted by

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[826] Ibid para 112.
[827] Ibid.
[828] Ibid.
[829] Ibid.
[830] The Constitution op cit note 810.
[831] Ibid; see also supremacy clause in section 2 of the Constitution.
[832] *Doctors for Life* op cit note 811.
[833] *Minister of Health v New Clicks SA (Pty) Ltd* 2006 (2) SA 311 (CC).

Parliament and 'deliberative legislative assemblies'.[834] Ngcobo J added, that our Constitution envisions a democratic government that is transparent, responsive and accountable, based on a balance between the principles of representative and participatory democracy, allowing the public an opportunity to participate in the creation of laws.[835] Moreover, he provided that the fundamental objective of public participation in law-making is to make certain that legislatures possess comprehensive knowledge, and are capable of responding effectively to societal needs.[836] He positioned that: 'when legislators are well-informed about these concerns, it enhances the legitimacy and subsequent acceptance of the legislation.'[837]

In this regard, the right to participate in the law-making process in South Africa is extensive. It is not only a constitutionally entrenched right, but given effect by various legislation, and participatory initiatives.[838] It is beyond the scope of this dissertation to discuss every instance of such right; thus, this analysis is confined to the right to participate in policy decisions, concerning health-related topics. Moreover, the specific content of said right, which corresponds with DPE goals and objectives.

The Constitution established the foundation for the right to public access to, and participation in the legislative process at all governmental levels.[839] In the national sphere (Parliament), sections 59(1)(a) and 72(1)(a) of the Constitution provide that the National Assembly (NA) and the National Council of Provinces (NCOP) should 'facilitate public involvement in the legislative and other processes of the Assembly/Council and its committees.'[840] Provincial legislatures are bound by a similar duty, as outlined in section 118(1)(a) of the Constitution.[841] In the local governmental sphere, a comparable mandate is issued by section 152(1)(e); however, instead of 'facilitating public involvement', it ought to 'encourage the involvement of communities and community organisations in the matters of local government.'[842] Moreover, in *Democratic Alliance v eThekwini Municipality*,[843] the SCA held that the duty of local governments to 'provide democratic and accountable government for local communities' enshrined in section 152(1)(a) of the Constitution, confers a similar

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[834] *Doctors for Life* op cit note 811 para 121.
[835] Ibid para 121–122.
[836] Ibid para 205.
[837] Ibid.
[838] See Kabingesi op cit note 121 at 41–48.
[839] Ibid at 41.
[840] The Constitution op cit note 810.
[841] Ibid.
[842] Ibid.
[843] *Democratic Alliance v eThekwini Municipality* 2012 (2) SA 151 (SCA).

obligation to facilitate public involvement in their legislative and executive affairs.[844] This obligation is further given effect by numerous statutory provisions, such as sections 17(2) and 51(1)(e) of the Local Government: Municipal Systems Act,[845] where the court held that municipal councils are required to 'establish appropriate mechanisms', that allow for the participation of local communities in local governance.[846]

On the contrary, although the Constitution provides a duty to 'facilitate public involvement', it does not define what this means or the extent to which such duty is required of legislatures. Therefore, it becomes crucial to refer to case law for clarification. These questions were precisely addressed in *Doctors for Life*,[847] where the court contended that the words 'facilitate public involvement' encompass a wide concept, primarily concerned with the duty to warrant public participation in the legislative process.[848] The term 'facilitate' is interpreted as the act of making something 'easy or easier', to 'promote' or 'help forward'.[849] 'Public involvement' is often used to indicate the process of public participation in decision-making.[850] Furthermore, the court highlighted that the definition of 'involve', as per the dictionary, means to 'bring a person into a matter', whilst 'participate' denotes 'taking part with others (in an action or matter);…the active involvement of members of a community or organisation in decisions which affect them.'[851] Therefore, the court concluded that the phrase, *facilitate public involvement in the legislative* process entails 'taking steps to ensure that the public participate in the legislative process.'[852] Accordingly, this duty necessitates that the aforementioned legislative bodies take the necessary measures to ensure the active involvement of the public in the law-making process, as persons affected by such decisions. However, the Constitution does not stipulate the steps or measures to be taken by legislatures. Moreover, the extent to which this duty is required. In *Doctors for Life*,[853] the court held that the Constitution intentionally omits this information, or the precise methods of public participation required, allowing legislatures a substantial degree of discretion to decide the most effective ways to carry out this duty, or on how to facilitate public involvement.[854]

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[844] Ibid para 23.
[845] The Local Government: Municipal Systems Act 32 of 2000.
[846] *Democratic Alliance* op cit note 843 para 23.
[847] *Doctors for Life* op cit note 811.
[848] Ibid para 119.
[849] Ibid.
[850] Ibid.
[851] Ibid.
[852] Ibid para 120.
[853] *Doctors for Life* op cit note 811.
[854] Ibid para 123.

Notwithstanding the level of discretion granted to legislative bodies in facilitating public involvement, the courts are still authorised to determine, when suitable, if this constitutional mandate has been executed adequately.[855] Significantly, the court developed a test, using 'reasonableness' as the standard measure against which the conduct of legislative bodies will be examined, in appropriate cases.[856] As such, the legislature must have taken the steps necessary to provide a 'reasonable opportunity' for effective public participation in the legislative process.[857] The court held that reasonableness is context-specific, in which the prevailing facts and circumstances of each case are important in determining whether the legislature had acted reasonably.[858] Thus, according to the test, the court will consider the following factors: (i) the nature and importance of the legislation in question; (ii) the intensity of the impact of the legislation on the public; (iii) other applicable factors, including time and expense.[859] Conversely, the court held that the reduction in expenses and time consumption alone, cannot justify the failure to provide sufficient avenues of public participation.[860] Thus, the court will consider what the legislature deemed as 'appropriate public involvement', given the 'content, importance and urgency' of the legislation.[861] Ultimately, the court emphasised that the duty to facilitate public involvement entails two key components.[862] Firstly, a duty to ensure 'meaningful opportunities' for the public to participate in the legislative process.[863] Secondly, a duty to implement measures that enable the public to maximise, or take advantage of the opportunities granted.[864] The court further held that the duty of the legislature to take steps to facilitate public involvement also means that it is incumbent upon them to inform the public, and provide information on prospective legislation.[865] This may be attained through educating the public and enhancing their capacity for participation.[866] According to Ngcobo J in his majority judgment:

> 'Public involvement in the legislative process requires access to information and the facilitation of learning and understanding in order to achieve meaningful involvement by ordinary citizens.

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[855] Ibid para 124.
[856] Ibid paras 125; 127.
[857] Ibid para 129.
[858] Ibid para 127.
[859] Ibid para 128.
[860] Ibid.
[861] Ibid.
[862] Ibid para 129.
[863] Ibid.
[864] Ibid.
[865] Ibid para 131.
[866] Ibid.

> In this regard, article 25 of the African Charter imposes an obligation on states parties to "promote and ensure through teaching, education and publication" the right to political participation.'[867]

Consequently, active participation by the general public in the legislative process does not only involve access to information, but also requires the 'facilitation of learning', ensuring that ordinary citizens have a better understanding of the legislative content, and can thus engage meaningfully.[868]

Sections 56(d) and 69(d) of the Constitution permit the NA and the NCOP, or any of their committees, 'to receive petitions, representations from any interested persons or institution.'[869] Furthermore, although these legislative bodies are at liberty to create their own rules and orders, they should do so with appropriate attention to the representative and participatory nature of our democracy, together with the principles of 'accountability, transparency and public involvement'.[870] In addition, they are obliged to execute their affairs in a public and open manner, ensuring public access to their sittings and committees, and cannot exclude such access, 'unless it is reasonable and justifiable to do so in an open and democratic society.'[871] The provincial legislatures are to follow the same protocol.[872] In this way, the public are allowed an opportunity to convey their interests, concerns, or suggestions to said legislative bodies, who are expected to be responsive, and formulate laws that incorporate or consider such public opinion.[873] In *Doctors for Life,*[874] the court held that public access to the legislative procedure is a crucial aspect in the facilitation of public involvement.[875] It enables the public to witness the discussions and debate that go into the formulation of laws, and their ability to make representations and submissions to the legislatures, enables them to actively contribute to this process.[876] Thus, the court held that the aforementioned constitutional provisions do, in fact, facilitate public involvement in the law-making process.[877]

However, as stated earlier, the Constitution grants considerable latitude to legislatures, who have the discretionary power to decide on the most effective and suitable means of

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[867] Ibid.
[868] Ibid.
[869] The Constitution op cit note 810.
[870] Ibid, section 57(1)(b) for the NA; section 70(1)(b) for the NCOP.
[871] Ibid, see section 59 for the NA and section 72 for the NCOP.
[872] Ibid sections 115(d), 116(1)(b) and 118.
[873] Kabingesi op cit note 121 at 42.
[874] *Doctors for Life* op cit note 811
[875] Ibid para 137.
[876] Ibid.
[877] Ibid para 136.

facilitating public involvement.[878] Thus, as highlighted in *Doctors for Life*,[879] legislatures may introduce innovative approaches and explore their own methods to achieve this objective, provided that they adhere to the criterion of reasonableness.[880] Furthermore, the court upheld the ruling in *King v Attorneys Fidelity Fund Board of Control,*[881] where the SCA expressed a similar perspective:

> 'Public involvement might include public participation through the submission of commentary and representations: but that is neither definitive nor exhaustive of its content… It is plain that by imposing on Parliament the obligation to facilitate public involvement in its processes, the Constitution sets a base standard, but then leaves Parliament significant leeway in fulfilling it.'

As such, legislatures are not constrained to the public participation mechanisms outlined in the Constitution, which appear the basic level of compliance expected of them.

The effective realisation of the right to public participation is not solely dependent on the constitutional provisions discussed earlier; it also relies on the existence of other fundamental human rights that are integral to our constitutional democracy. These rights encompass; the right to *equality*, *freedom of expression* and *human dignity* (among others), which also serve as the foundational values of our democracy.[882] While my primary focus is not to perform an extensive examination of said rights, I will briefly highlight their role in enhancing the right to public participation.

Section 9(1) of the Constitution declares the right to equality, in which everyone is viewed as equal before the law, and is entitled to the 'equal protection and benefit of the law.'[883] The right to equality also entails 'the full and equal enjoyment of all rights and freedoms.'[884] Moreover, the state is prohibited from directly or indirectly engaging in unfair discrimination against anyone on the basis of any of the grounds listed in the section.[885] In the context of public participation, it is imperative that legislatures guarantee every citizen an equal opportunity to engage in the legislative process, without unfairly excluding anyone on the basis of any of the grounds listed in subsection 3.[886] This draws emphasis on the importance of

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[878] Ibid para 145.
[879] Ibid.
[880] Ibid.
[881] *King v Attorneys Fidelity Fund Board of Control* 2006 (1) SA 474 (SCA) para 22.
[882] The Constitution op cit note 810, section 1.
[883] Ibid.
[884] Ibid at section 9(2).
[885] Ibid at section 9(3).
[886] Ibid.

inclusive public participation, which is accessible to all. Thus, establishing a platform where a wide range of voices can actively and collectively contribute to the legislative process.

The right to freedom of expression is often perceived as the backbone of our democracy, giving effect to, and providing support to other human rights.[887] It is not only acknowledged as a fundamental human right in South Africa, but recognised internationally through various international instruments.[888] To be precise, it is articulated in Article 19 of the International Covenant on Civil and Political Rights (ICCPR)[889] and the Universal Declaration of Human Rights (UDHR).[890] In the South African context, section 16 of the Constitution provides that:

> '(1) Everyone has the right to freedom of expression, which includes:
>
> (a) freedom of the press and other media;
>
> (b) freedom to receive or impart information or ideas;
>
> (c) freedom of artistic creativity; and
>
> (d) academic freedom and freedom of scientific research.'[891]

While the Constitution observes only four dimensions to the right to freedom of expression, the term 'includes' denotes that it may be expressed in various other forms.[892] The right to freedom of expression is a wide-ranging concept, essentially encompassing 'the right to seek, hear, read and wear'.[893]

In providing greater depth to said right within a democratic setting, the Constitutional Court in *Democratic Alliance v African National Congress*[894] held that:

> 'It [freedom of expression] is valuable both for its intrinsic importance and because it is instrumentally useful. It is useful in protecting democracy, by informing citizens, encouraging

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[887] WJ van Vollenhoven 'The right to freedom of expression: The mother of our democracy (2015) 18(6) *Potchefstroom Electronic Law Journal* 2299–2327 at 2299.

[888] Ibid.

[889] International Covenant on Civil and Political Rights UNGA Res 2200, UN GAOR, 21st Sess, Supp No 16, UN Doc A/6316 (1966), 993 UNTS 171.

[890] Universal Declaration Of Human Rights, UN General Assembly (10 December 1948) 217 A (III).

[891] The Constitution op cit note 810.

[892] Van Vollenhoven op cit note 887 at 2302.

[893] Ibid at 2302.

[894] *Democratic Alliance v African National Congress* 2015 (2) SA 232 (CC), as cited in DW Thaldar & M Steytler 'Time for Cinderella to go to the ball: Reflections on the right to freedom of scientific research' (2021) 138(2) *South African Law Journal* 260–288 at 271.

> debate and enabling folly and misgovernance to be exposed. It also helps the search for truth by both individuals and society generally. If society represses views it considers unacceptable, they may never be exposed as wrong. Open debate enhances truth-finding and enables us to scrutinise political argument and deliberate social values.'[895]

Given this ruling, the right to freedom of expression becomes pivotal in facilitating public engagement in the legislative process. It empowers citizens to voice their perspectives freely, and engage in constructive debates within Parliament, while benefiting from exposure to differing viewpoints, and influencing the law-making process.[896] This liberty enhances the pursuit of truth, enabling citizens to scrutinise governmental actions and political issues by contributing their insights. Without this right, meaningful participation in the legislative process would be challenging.

Consequently, South Africa places significant value on the right to freedom of expression, particularly in the context of its historical limitations, where citizens faced repercussions for criticising governmental practices in the past.[897] Furthermore, the nation's transition and commitment to a new culture, founded on the principles of transparency, accountability and justification (for actions).[898] However, it is crucial to note that the right to freedom of expression is not absolute, and cannot be used to promote hate speech (amidst other things).[899]

Significantly, in addition to its purpose of pursuing truth, a substantial body of legal precedents highlight the ability of freedom of expression to enhance individual autonomy, and thus human dignity.[900] In *Democratic Alliance*,[901] the court held that:

> 'What is more, being able to speak freely recognises and protects "the moral agency of individuals in our society". We are entitled to speak out not just to be good citizens, but to fulfil our capacity to be individually human.'[902]

In a similar vein, in *Case v Minister of Safety and Security*,[903] Mokgoro J in her minority judgment contended that:

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[895] Ibid para 122.
[896] Ibid.
[897] Van Vollenhoven op cit note 887 at 2302.
[898] Ibid at 2301.
[899] See section 16(2)(a)(b)(c) of the Constitution op cit note 810.
[900] Thaldar & Steytler op cit note 894.
[901] *Democratic Alliance* op cit note 894, as cited in Thaldar & Steytler op cit note 894 at 271.
[902] Ibid para 123.
[903] *Case v Minister of Safety and Security* 1996 (3) SA 617 (CC), as cited in Thaldar op cit note 894 at 271.

> 'The most commonly cited rationale is that the search for truth is best facilitated in a free "marketplace of ideas." That obviously presupposes that both the supply and the demand side of the market will be unfettered. But of more relevance here than this "marketplace" conception of the role of free speech is the consideration that freedom of speech is a sine qua non for every person's right to realise her or his full potential as a human being, free of the imposition of heteronomous power. Viewed in that light, the right to receive others' expressions has more than merely instrumental utility, as a predicate for the addressee's meaningful exercise of her or his own rights of free expression. It is also foundational to each individual's empowerment to autonomous self-development.'[904]

The above judgments substantiate the close nexus between freedom of expression and individual autonomy. They elucidate the crucial function of the former in enabling self-development,[905] improving moral judgments and allowing for self-fulfilment or greater happiness.[906] Thus, it is only through this freedom that one may exercise proper self-governance.

In the South African constitutional setting, the significance of *individual autonomy* can be attributed to its role as an essential component of human dignity, which is outlined in section 10 of the Constitution.[907] In *Barkhuizen v Napier,*[908] the majority firmly held that individual autonomy is 'a vital part of dignity'.[909] Moreover, in *Member of the Executive Council for Education: KwaZulu-Natal v Pillay*,[910] the Constitutional Court reinforced this idea, declaring that a fundamental aspect of the freedom and dignity of a person is the 'entitlement to respect for the unique set of ends that the individual pursues.'[911] The court also endorsed the minority judgment of Justice Ackermann in *Ferreira v Levin*,[912] where he further clarified the interrelation between freedom, autonomy and human dignity, asserting that:[913]

> 'Human dignity has little value without freedom; for without freedom *personal development and fulfilment* are not possible. Without freedom, human dignity is little more than an abstraction.

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[904] Ibid para 26.

[905] 'Self-development refers to the gradual development of one's abilities and characteristics', see Thaldar & Steytler op cit note 894 at 272.

[906] Thaldar & Steytler op cit note 894 at 272, 273.

[907] Ibid; 'Everyone has inherent dignity and the right to have their dignity respected and protected,' see the Constitution op cit note 810.

[908] In *Barkhuizen v Napier* 2007 (5) SA 323 (CC), Thaldar & Steytler op cit note 894 at 273.

[909] Ibid para 57.

[910] *Member of the Executive Council for Education: KwaZulu-Natal v Pillay* 2008 (1) SA 474 (CC), as cited in Thaldar & Steytler op cit note 894 at 273.

[911] Ibid para 64.

[912] *Ferreira v Levin* 1996 (1) SA 984 (CC), as cited in Thaldar & Steytler op cit note 894 at 273.

[913] Ibid para 49.

> Freedom and dignity are inseparably linked. To deny people their freedom is to deny them their dignity.’ [914]

Thus, these values do not exist in a vacuum, but are inherently interconnected. As Justice O’Regan, in her minority judgment in *NM v Smith*,[915] had emphasised:

> ‘Recognising the role of freedom of expression in asserting the moral autonomy of individuals demonstrates the close links between freedom of expression and other constitutional rights such as human dignity, privacy and freedom. Underlying all these constitutional rights is the constitutional celebration of the possibility of morally autonomous human beings independently able to form opinions and act on them.’[916]

It is worth mentioning that this minority judgment was supported by a full bench of the SCA[917] in *British American Tobacco South Africa (Pty) Ltd v Minister of Health*.[918] Ultimately, in the realm of public participation, it can be inferred that, by virtue of freedom of expression, citizens have the liberty to articulate their individual viewpoints as autonomous beings, actively contributing to the formulation of societal laws.

In essence, the right to public participation, streamlined by the aforementioned constitutional values, means that citizens ought to be granted an *equal* opportunity to participate, and *freely* voice their opinions in the legislative process, as *autonomous* individuals capable of self-governance. This reinforces and champions their fundamental human rights to equality, freedom of expression and human dignity.

Various statutory provisions also serve to implement the right to public participation, some empowered by the constitutional provisions expressed above.[919] To provide examples:

*(1) The Powers, Privileges and Immunities of Parliament and Provincial Legislatures Act*[920]

The Powers, Privileges and Immunities of Parliament and Provincial Legislatures Act sought to define and establish the specific ‘powers, privileges and immunities’ of National and provincial legislatures, together with their members and delegates.[921] Whilst this Act does not

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[914] Ibid; *Pillay* op cit note 910 para 63.
[915] *NM v Smith* 2007 (5) SA 250 (CC), as cited in Thaldar & Steytler op cit note 894 at 274.
[916] Ibid para 145.
[917] Thaldar & Steytler op cit note 894 at 273–274.
[918] *British American Tobacco South Africa (Pty) Ltd v Minister of Health* [2012] 3 All SA 593 (SCA), as cited in ibid at 273.
[919] See Kabingesi op cit note 121 at 42 –45.
[920] The Powers, Privileges and Immunities of Parliament and Provincial Legislatures Act 4 of 2004.
[921] Kabingesi op cit note 121 at 42.

provide guidance on how legislatures ought to facilitate public participation, Chapter 5 empowers a joint committee to summon witnesses to provide testimonies (under oath), or tender documents; or call upon 'any person or institution to report to it' during proceedings.[922]

### *(2) The Money Bills Amendment Procedure and Related Matters Act*[923]

This Act permits the National and Provincial legislatures to oversee the allocation and expenditure of public funds.[924] Section 5 authorises committees within the NA to conduct annual assessments on departmental performance, and to prepare 'budgetary review and recommendation reports (BRRRs)' for submission to the appropriate Minister.[925] These BRRRs are often formally presented in Parliament, and subjected to debate before they are reported to the appropriate Minister.[926] This enables the general public, or interested persons to provide their feedback on departmental performance and the allocation of public funds, thus incorporating an element of public participation.[927] In addition, section 8(2) provides that 'the committees must conduct joint public hearings on the fiscal framework and revenue proposals'.[928] As such, this demonstrates the legislature's commitment to incorporating public opinion, and facilitating public involvement in matters of public revenue.[929]

### *(3) Promotion of Administrative Justice Act*[930]

The Promotion of Administrative Justice Act (PAJA) is among the statutes that establish a legal framework for public participation in the legislative process.[931] It serves to uphold the right to administrative action, in which everyone is entitled to administrative action which 'is lawful, reasonable and procedurally fair'.[932] This includes the right to receive 'written reasons' when administrative action 'adversely' affects the rights of an individual.[933] Accordingly, it ascertains that state actors are held accountable for their conduct or decisions.[934] As a state entity, Parliament is obliged to ensure that the public are informed, and supplied with adequate

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[922] Ibid.
[923] The Money Bills Amendment Procedure and Related Matters Act 9 of 2009.
[924] Kabingesi op cit note 121 at 43.
[925] Ibid.
[926] Ibid.
[927] Ibid.
[928] The Money Bills Amendment Procedure and Related Matters Act op cit note 889.
[929] Kabingesi op cit note 121 at 43.
[930] Promotion of Administrative Justice Act 3 of 2000.
[931] Kabingesi op cit note 121 at 44.
[932] Section 33(1) of the Constitution op cit note 810.
[933] Section 33(2) ibid.
[934] Kabingesi op cit note 121 at 44.

information on national legislation, or relevant matters that are being considered.[935] Furthermore, PAJA makes for provision for how Parliament ought to conduct its decision-making procedures, precisely those that affect the general public.[936] As such, the implementation of PAJA within Parliamentary practices establishes a platform for citizens to voice their opinions and contribute to the decision-making procedure, ultimately enhancing transparency in parliamentary operations.[937]

The legislation mentioned above are mere examples of public participation initiatives. Nevertheless, when considering the promotion of public engagement in matters related to health (HHGE), it becomes crucial to focus on the National Health Act (NHA).[938]

### *(4) The NHA*

In contemporary health policy frameworks, the involvement of communities in the healthcare system is increasingly recognised as a pivotal element of any health polices founded on human rights.[939] Public participation as a significant component of primary healthcare has gained international consensus, outlined in the Declaration of Alma-Ata.[940] South Africa's enduring commitment to public participation was reaffirmed in the White Paper on Transformation of the Health System in South Africa (White Paper), which sought to promote the participation of communities throughout the health sector.[941] Thus, section 29 of the NHA establishes a District Health System (DHS), comprising of the numerous health districts. Section 31(1) provides for the development of District Health Councils in every health district within a Province,[942] which aim to improve relations between service providers and citizens, creating avenues for communities to participate in health policy decisions.[943] These councils were established to ensure that local communities exercise increased influence in shaping health policies, highlighting the legislatures commitment to '"community participation and empowerment"'.[944] Section 21(2)(h) of the NHA also makes provision for the director general to 'promote community participation in the planning, provision and evaluation of health services', aligning

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[935] Ibid.
[936] Ibid.
[937] Ibid.
[938] The National Health Act op cit note 46.
[939] BM Meier, C Pardue, & L London 'Implementing community participation through legislative reform: a study of the policy framework for community participation in the Western Cape province of South Africa' (2012) 12 *BMC International Health and Human Rights* 1–14 at 2.
[940] Ibid.
[941] Ibid at 4.
[942] The National Health Act op cit note 46.
[943] Meier op cit note 939 at 4.
[944] Ibid.

with national health policy. However, the NHA does not provide much detail on how community participation ought to be facilitated.

*Parliamentary initiatives*: *The Public Participation Model (PPM)*

The Public Participation Model established by the 5th Parliament in 2015 represented a great initiative in creating a standards-based structure for public participation.[945] This project originated with the objective of improving the calibre of public participation and to allow greater public access to such opportunities, incorporating the principles of accountability and transparency as enshrined in the Constitution.[946] Considering that public participation was becoming a vital component of the legislative process and in upholding its participatory democracy; moreover, the increased enforcement of this right, Parliament formulated a strategy to institutionalise public participation.[947] Thus, this led to the creation of PPM, which provided the minimum standards required for the facilitation of public participation during Parliamentary proceedings.[948] This model of public participation encompasses four stages, namely, to inform, consult, involve and provide feedback. These stages are discussed briefly below.

1) Inform: This stage centers on the provision of *access to information*.[949] It requires that citizens be supplied with sufficient information on the legislation under consideration.[950] The public education office is usually tasked with enlightening the public on such matters.[951]

2) Consult: This stage emphasises creating *opportunities for public opinion*.[952] It requires Parliament to provide notice to, and invite the public to share their opinions.[953] In this way, the public are equipped with the necessary information to prepare, formulate and articulate their claims.[954]

3) Involve: This stage places emphasis on creating a platform for *dialogue* and *interaction* in Parliament.[955] Citizens should be granted a chance to express their viewpoints during Parliamentary proceedings, or committee meetings, and thus engage in public dialogue and

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[945] Kabingesi op cit note 121 at 35.
[946] Ibid.
[947] Ibid at 35–36.
[948] Ibid at 36.
[949] Ibid.
[950] Ibid.
[951] Ibid.
[952] Ibid.
[953] Ibid.
[954] Ibid.
[955] Ibid.

interaction with others.[956] Thus, it is crucial in ensuring that citizens are in fact able to contribute to the legislative process, or influence the policy outcome.[957]

4) Feedback: This stage focuses on the provision of *feedback* on the *outcome* of the process.[958] Thus, Parliament is to furnish information and report on the outcome of the relevant decision.[959] Whilst providing necessary updates, it should oversee the progress of the decision made. [960]

*(b) DPE and South Africa*

Deliberative democracy, although often associated with Eurocentric beliefs, is not a novel concept in South Africa, but such practices had manifested in traditional African communities, considering Kenneth Kaunda's statement: 'In our original societies we operated by consensus. An issue was talked out in solemn conclave until such time as agreement could be achieved.'[961] Moreover, in *Mogale v Speaker of the National Assembly*,[962] Theron J in a more recent Constitutional Court majority judgment held that 'deliberative democracy is familiar to South Africans', precisely in the context of 'traditional communities' that are affected by the Traditional and Khoi San Leadership Act.[963] The court also referred to *Doctors for Life,* where Ngcobo J also commented on participatory practices in traditional African communities such as 'imbizo/lekgotla/bosberaad' which are still observed in traditional societies, where the community would engage in discussions to address matters that impacted them.[964] This is further corroborated by Nelson Mandela is his autobiography, cited in *Mogale.*[965] In recollecting his childhood memories, he recounted witnessing a form of deliberative democracy practiced in community meetings.[966] In his words:

> 'Everyone who wanted to speak did so. It was democracy in its purest form . . . everyone was heard: chief and subject, warrior and medicine man, shopkeeper and farmer, landowner and labourer . . . all . . . were free to voice their opinions and were equal in their value as citizens.'[967]

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[956] Ibid at 37.
[957] Ibid.
[958] Ibid at 36.
[959] Ibid at 37.
[960] Ibid.
[961] Ani op cit note 508 at 211.
[962] *Mogale v Speaker of the National Assembly* 2023 (9) BCLR 1099 (CC) para 4.
[963] The Traditional and Khoi San Leadership Act 3 of 2019.
[964] *Doctors for Life* op cit note 811 para 101.
[965] *Mogale* op cit note 962 para 4.
[966] Ibid.
[967] Ibid.

While these historical practices are not binding on contemporary South African participatory democracy, they do lend support to the idea that deliberative elements may have deep historical roots in African societies.[968]

The idea of deliberation in South African practices can also be traced back to the Truth and Reconciliation Commission (TRC) established after apartheid; a pivotal institution in South Africa's transition to a constitutional democracy.[969] The TRC was instrumental in providing redress to past injustices and gross human rights violations that occurred during the apartheid era, offering perpetrators the opportunity to openly confess their crimes in exchange for amnesty (an official pardon).[970] Its main objective was to 'promote national unity and reconciliation in a spirit of understanding which transcends the conflicts and divisions of the past.'[971]

A key feature of the TRC was the manner in which it conducted its public hearings.[972] It offered an inclusive platform, in which anyone could participate in the discussions, and notably, even assess the Commission itself (make open criticisms).[973] Furthermore, central to its approach was the pursuit of 'dialogue truth'; a method that sought to uncover the truth through 'interaction, discussion and debate'.[974] This approach ensured that all perspectives were considered and weighed against each other.[975] Additionally, it was within this process of dialogue and mutual respect that a framework for fostering transparency, democracy, and societal engagement emerged.[976] This framework ensured the upholding of human dignity and integrity.[977] The TRC had also achieved remarkable success in its attempts.[978]

As such, it is against this historical context (as stated in *Doctors for Life)*[979] that the nature of our novel constitutional democracy should be understood, or more precisely, the right to public participation. As visible in the TRC proceedings, the elements of 'dialogue' and 'mutual respect', also crucial elements of deliberative democracy, were significant in

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[968] Ibid.
[969] JL Gibson 'The Truth about Truth and Reconciliation in South Africa' (2005) 26(4) *International Political Science Review* 341–361 at 341, 343 available at http://www.jstor.org/stable/30039021, accessed on 03/09/2023.
[970] Ibid at 344.
[971] Ibid.
[972] Truth and Reconciliation Commission 'Truth and Reconciliation Commission of South Africa Report' (1998) at 114 available at https://www.justice.gov.za/trc/report/finalreport/volume%201.pdf, accessed on 03/09/2023.
[973] Ibid at 113–114.
[974] Ibid at 113.
[975] Ibid.
[976] Ibid at 114.
[977] Ibid.
[978] Gibson op cit note 969 at 344.
[979] *Doctors for Life* op cit note 811 para 112.

enhancing transparency, democracy and public participation.[980] Such values, which are now constitutionally entrenched, are portrayed above.

South Africa's progression towards a more participatory democracy stems not only from its historical legacy but also from the realities of a dynamic society, where representative democracy is increasingly viewed as 'ill-suited to the problems of the 21st Century'.[981] The roles and responsibilities of the government have evolved to become increasingly intricate, politically charged, and diverse.[982] As a result, the traditional system of representative democracy may no longer effectively address the challenges and issues that have arisen in this modern era,[983] specifically the regulation of modern technologies, such as CRISPR-Cas9 and HHGE. It requires a democracy that transcends mere good governance, in which the quality of said democracy is assessed by its level of 'participation, representation, accountability, transparency and responsiveness'.[984] Accordingly, the ideal model of democracy accentuates:

> '[T]he use of power and the management of conflict. [Democracy] requires a set of political institution and processes based on the principles of popular control (own emphasis) over public decisions and decision makers, and equality of respect and voice (own emphasis) between citizens in the exercise of that control.'[985]

As such, public participation is not only an essential aspect of good governance,[986] but also the ideal democracy.[987] It is not merely an abstract concept, but should be a concrete practice.[988] Consequently, democracy cannot be reduced to mere voting, but requires an active citizenry that can directly impact legislative decisions, emphasising elements such as social dialogue, equality and mutual respect.[989] This form of public participation has the ability to:

1) enhance the legitimacy and quality of governmental decisions and actions;[990]
2) ensure that citizens comply with legal policies;[991]

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[980] Truth and Reconciliation Commission op cit note 972 at 113.
[981] JP Govender, S Reddy & P Pillay 'Dimensions of participation and implementation in South African local government' (2011) 19(3) *Administratio Publica* 183 –208 at 188.
[982] Ibid.
[983] Ibid.
[984] Ibid at 189.
[985] Ibid.
[986] Ibid at 188.
[987] Ibid at 189.
[988] Ibid.
[989] Ibid at 188, 189.
[990] Ibid at 189.
[991] Ibid.

3) prompt policymakers to create room for public input in their decision-making processes; and[992]
4) improve a democracy based on the people.[993]

Consequently, this *ideal democratic model* is inherently deliberative, considering the goals and objectives of DPE. Furthermore, the literature reveals that deliberative democracy is often elevated in government reform.[994] However, this dissertation does not prioritise deliberative participation as the sole means to achieve good governance but regards it as a vital element.[995]

It is crucial to emphasise that the ideal democratic model expressed above, strongly aligns with the goals and objectives of participatory democracy in South Africa, as I have expressed through the nature and scope of the right to public participation. Furthermore, the introduction of the Public Participation Model by Parliament, further underscores the significance of deliberative elements within its participatory framework.[996] Ultimately, to highlight the key similarities that the South African participatory democratic framework shares with the DPE technique:

1) It places emphasis on the values of transparency, accountability and responsiveness in public participation;[997]
2) The right to public participation is a concrete right, in which legislatures should take steps to facilitate public participation in the legislative process;[998]
3) Its primary objective of public participation in the legislative process is to guarantee that legislation is 'informed and responsive', to enhance its legitimacy;[999]
4) It also ensures that legislatures are informed and better understand public concerns;[1000]
5) It makes provision for active participation in the legislative process, in which 'participate' means, '"…the active involvement of members of a community or organization in decisions which affect them."'[1001]

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[992] Ibid.
[993] Ibid.
[994] Ibid.
[995] See ibid at 190.
[996] Kabingesi op cit note 121 at 35.
[997] The Constitution op cit note 810.
[998] Ibid.
[999] *Doctors for Life* op cit note 811 para 205.
[1000] Ibid.
[1001] Ibid para 119.

6) Public involvement entails the responsibility to inform and educate the public about potential legislation, thereby enhancing their capacity for meaningful participation;[1002]
7) The right to public participation is also supported by the rights to equality, freedom of expression, and human dignity, thus enabling, open, equal and unrestricted public debate;[1003]
8) The PPM model introduces elements like 'dialogue and interaction', thus enabling exposure to differing arguments in parliamentary hearings.[1004]

Therefore, I contend that DPE aligns with the South African constitutional framework in the abovementioned ways.

Additionally, while the South African constitutional framework does not explicitly provide for the DPE technique, the considerable discretion afforded to legislatures in fulfilling their constitutional mandate to facilitate public participation[1005] suggests that DPE may be explored as an innovative supplementary tool within the country's participatory democracy. However, this issue falls outside of the scope of the current study. It is therefore important to emphasise that this study does not equate DPE with participatory democracy in South Africa but rather argues that it fits well with the country's core democratic values and culture, and should be welcomed as a complementary mechanism.

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[1002] Ibid para 131.
[1003] The Constitution op cit note 810.
[1004] Kabingesi op cit note 121 at 35.
[1005] *Doctors for Life* op cit note 811 para 123.

# *CHAPTER 3*

## *DATA ANALYSIS METHODOLOGY*

### I INTRODUCTION

The utilisation of DPE in health science research enables the integration of community and expert knowledge, where academic research is supplemented with real-world action.[1006] Historic models of primary health care allude to the idea of social justice, emphasising collective efforts or community participation in public health care decision-making.[1007] Accordingly, DPE establishes a forum where the public, experts and various stakeholders can collaboratively reach legitimate and actionable solutions through an equal exchange of knowledge in respectful and reasoned deliberations.[1008] This approach proves particularly useful when addressing complex policy decisions such as the regulation of HHGE, in its ability to yield valuable data encompassing various perspectives.[1009]

The analysis of DPE data becomes challenging for conventional methods of qualitative analysis due to its dialogic nature.[1010] However, there are no methodologies specifically designed for deliberation data analysis, or which adhere to the unique features of said data, particularly shifts in public opinion.[1011] Plamondon, Bottorff and Cole suggest that the analysis of DPE data requires a balance between *analytic* and *interpretive* strategies to ensure that the methodological framework is credible or trustworthy, whilst upholding core deliberative elements such as inclusivity and active participation.[1012] However, the proposed framework provides analytical guidance instead of a distinct methodology for DPE data analysis.[1013] Thus, with the objective to garner informed public perspectives on the clinical applications of HHGE in South Africa using DPE, this study has employed a qualitative analysis methodology, namely, thematic analysis, to answer the *why* question in relation to the research participants'

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[1006] E Blacksher 'Participatory and Deliberative Practices in Health: Meanings, Distinctions, and Implications for Health Equity' (2013) 9(1) *Journal of Public Deliberation* 1–20 at 9, 10; KM Plamondon, JL Bottorff & DC Cole 'Analyzing Data Generated through Deliberative Dialogue: Bringing Knowledge Translation into Qualitative Analysis' (2015) 25(11) *Qualitative Health Research* 1–11 at 1.
[1007] Blacksher ibid at 7.
[1008] Plamondon, Bottorff & Cole op cit note 1006 at 1, 2; Blacksher ibid at 1.
[1009] Plamondon, Bottorff & Cole ibid at 1; Blacksher ibid at 9.
[1010] Plamondon, Bottorff & Cole ibid at 1, 2.
[1011] O'Doherty op cit note 12 at 1, 3, 7; Plamondon, Bottorff & Cole op cit note 1006 at 2, 3.
[1012] Plamondon, Bottorff, and Cole op cit note 1006 at 1, 3.
[1013] Ibid at 9.

held perspectives and possible transformations.[1014] This methodology, although not deliberative-specific, appears to be a conventional data analysis approach in various DPE studies, and may be advantageous for research within a participatory paradigm.[1015] Furthermore, in its theoretical flexibility, it can be adapted to suit the research objectives of the study and DPE data analysis.[1016]

This chapter focuses primarily on the data analysis methodology adopted in the study, outlining the various stages of the analysis and its limitations. Thus, it has been divided into three sections, namely, (i) Qualitative research methodologies; (ii) Trustworthiness; and (iii) Data analysis procedure.

## II QUALITATIVE RESEARCH METHODOLOGIES

Qualitative methodologies have become increasingly prevalent in health care research to investigate behavioural patterns in health, lived experiences, health necessities and to design responsive strategies.[1017] If defined widely, qualitative research consists of various methods and ideologies which aim to address the *why* and *how* of the human experience, using specific research techniques (such as focus group discussions, interviews, etc).[1018] Thus, it may be used to provide detailed explanations (why) on research topics, or describe (how) human behaviour or procedures.[1019] Qualitative research remains distinguishable in its capacity to reveal the *emic* or *inside* perspective, or to understand issues, behaviour or occurrences through the lens of the study sample.[1020] Accordingly, it may be used to navigate complex policy decisions which value and incorporate the insights of the study sample.[1021] Moreover, to provide a contextually detailed understanding of the subject under investigation.[1022] As Denzin and Lincoln have provided, it 'involves an interpretive, naturalistic approach to the world,' enabling qualitative researchers to 'study things in their natural settings, attempting to make sense of, or interpret,

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[1014] M Hennink, I Hutter & A Bailey *Qualitative research methods* 2 ed (2020) 22.
[1015] Bartlett et al op cit note 197 at 751; see Puzhko, Gagnon & Simard op cit note 197 at 6; see Longo et al op cit note 197; see Longo, Rahimzadeh & Bartlett op cite note 197 at 5; Braun & Clarke op cit note 216 at 37.
[1016] Braun & Clarke ibid at 5; LS Nowell et al op cit note 250 at 2.
[1017] V Renjith et al Qualitative methods in health care research (2021) 12(1) *International journal of preventive medicine* 1–7 at 1.
[1018] Hennink, Hutter & Bailey op cit note 1014 at 21, 22.
[1019] Ibid at 22.
[1020] Ibid.
[1021] Ibid.
[1022] Ibid.

phenomena in terms of the meanings people bring to them'.[1023] As such, this study has opted for a qualitative research method to analyse the transcripts from the deliberations.

Qualitative research may be conducted under various paradigms or traditions, including interpretivism, semiotics, poststructuralism, etc.[1024] However, this dissertation is interested in the *interpretive paradigm* discussed below.[1025]

### *(a) The interpretive paradigm*

In social science research, there are two prevailing paradigms that serve as foundational frameworks.[1026] These are known as the *positivist* and *interpretive* paradigms.[1027] Although the interpretive paradigm is often associated with qualitative research, certain qualitative research methodologies (for instance, the traditional content analysis and grounded theory) display positivist elements or vice versa.[1028]

The positivist paradigm is characterised by its scientific and objective research approach, where reality is measured objectively and perceived as 'value-free'.[1029] Frequently utilised in quantitative research and experimental studies, it involves the development of hypotheses based on statistical data or theoretical constructs, which are subsequently tested against empirical evidence.[1030] As such, the positivist paradigm aims to minimise subjective influences on the collection and analysis of data, ensuring the isolation of facts from human values and contextual factors.[1031] However, this approach has been criticised in its belief that research can be completely objective.[1032] Furthermore, it overlooks the human nature of researchers or the 'interactive and co-constructive nature of data collection with human beings'.[1033] Consequently, the interpretive paradigm had materialised.

Following the constraints of the positivist paradigm in capturing the subjective dimensions of human experiences, the interpretive paradigm emerged.[1034] The interpretive

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[1023] Ibid.

[1024] Ibid at 23.

[1025] Ibid at 22.

[1026] Ibid. A *paradigm* is defined as a 'framework or lens' through which reality is interpreted. It consists of three components, such as ontology (how reality is perceived); epistemology (what qualifies as evidence or knowledge?) and methodology (the methods used for inquiry), see ibid at 23.

[1027] Ibid at 22.

[1028] Ibid at 26.

[1029] Ibid.

[1030] Ibid.

[1031] Ibid.

[1032] Ibid.

[1033] Ibid.

[1034] Ibid.

paradigm believes in varied interpretations of reality instead of presupposing a single, objective truth.[1035] Thus, grounded in philosophical traditions such as phenomenology, ethnography, hermeneutics and symbolic interactionism, interpretivism derives meaning from subjective interpretations of reality.[1036] It recognises the intrinsic subjectivity present in people's experiences or perceptions of reality.[1037] Therefore, instead of placing emphasis on facts or value-free outcomes, the interpretive paradigm acknowledges that the researcher's values and background may impact the way the data is collected and interpreted in research.[1038]

The interpretive paradigm accentuates the *emic* perspective.[1039] It aims to uncover unique insights about reality or the real-life experiences of people from their very own perspectives.[1040] Moreover, at its core is the idea that reality is constructed and shaped by the social, cultural, and historical contexts in which people exist.[1041] In other words, while individuals actively make sense of their experiences, such sense-making is a shared process within a larger social context, creating common interpretations which are collectively understood by everyone.[1042] This larger social context becomes crucial when studying human behaviour.[1043] Thus, as with qualitative research, 'interpretation and observation' are significant components in understanding or uncovering this reality or the social context.[1044]

*(b) Qualitative vs quantitative research*

Research is executed with the objective to deduce inferences or reach conclusions on phenomena through a systematic investigation or inquiry.[1045] Before conducting research, an appropriate research design is adopted to serve as a guiding framework in the research process.[1046] Accordingly, researchers may employ a quantitative or qualitative research design, depending on the objectives of the study.[1047]

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[1035] Ibid.
[1036] Ibid.
[1037] Ibid.
[1038] Ibid.
[1039] Ibid.
[1040] Ibid.
[1041] Ibid.
[1042] Ibid.
[1043] Ibid.
[1044] Ibid.
[1045] B Kandel 'Qualitative versus quantitative research' (2020) 32(5) *Journal of Product Innovation Management* 1–5 at 1.
[1046] Ibid at 2.
[1047] Ibid.

Quantitative research involves the analysis of numerical data utilising statistical techniques or mathematical methods to interpret phenomena or develop hypotheses.[1048] As such, it is typically associated with an objective, positivist paradigm which aims to determine statistical patterns, frequencies, averages or correlations through the measurement and counting of research issues.[1049] These findings are then extrapolated to a wider population.[1050] On the other hand, qualitative research methods are more aligned with the interpretive paradigm, and are adopted for the analysis of textual materials, producing a contextualised, in-depth understanding of reality.[1051] While this study primarily gravitates towards the latter, it is crucial to differentiate between these two research designs to grasp the essential nature of qualitative research employed in the study. Table 2.1 below highlights their fundamental differences.

*Table 2.1: Qualitative and quantitative research methods*[1052]

| | Qualitative research methods | Quantitative research methods |
|---|---|---|
| Research objectives | Aim to provide a contextual interpretation of behaviour, motivation and beliefs, while addressing the following questions:[1053]<br>(i) Why?<br>(ii) How?<br>(iii) What is the context? | Aim to measure, quantify or count data, addressing the following inquiries:[1054]<br>(i) How much?<br>(ii) How frequent?<br>(iii) What is the proportion? |
| Data-type | Uses textual data or words.[1055] | Uses numerical data or numbers.[1056] |
| Sample size | Small participant pool, usually a targeted selection.[1057] | Large, representative sample.[1058] |

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[1048] Ibid.
[1049] Hennink, Hutter & Bailey op cit note 1014 at 27, 28; Kandel op cit note 1045 at 2.
[1050] Hennink, Hutter & Bailey ibid at 27.
[1051] Ibid at 27, 28.
[1052] Ibid.
[1053] Ibid at 27.
[1054] Ibid.
[1055] Ibid.
[1056] Ibid.
[1057] Ibid.
[1058] Ibid.

| | | |
|---|---|---|
| Data collection | Group discussions, comprehensive interviews and observation.[1059] | Opinion polls, surveys, etc.[1060] |
| Analysis method | Conducts an interpretive examination.[1061] | Conducts a statistical examination.[1062] |
| Research outcome | To understand and explain phenomena, such as behaviour, actions or beliefs.[1063] | To determine patterns, frequencies and averages within a dataset to produce generalisations about the wider population.[1064] |

## III TRUSTWORTHINESS

DPE data presents a unique dataset, derived from purposeful dialogue.[1065] It embodies various perspectives and is influenced by the interpretive contributions of research participants.[1066] As such, said data distinguishes itself from traditional extractive methods where the researcher assumes the central role of interpreting meaning.[1067] Deliberation data emerges collaboratively as participants jointly engage with the subject matter, producing new knowledge and understandings based on research evidence (either scholarly publications or evidence obtained from the research itself) and their implicit knowledge.[1068]Accordingly, data generated through DPE has the potential to facilitate 'evidence-informed policymaking', creating a platform for various voices to collaborate and decide critical policy issues.[1069] Thus, it ensures that valuable research is accessible to decision-makers, empowering subsequent actions undertaken by stakeholders.[1070] As such, the analysis phase becomes crucial in realising this potential. However, before conducting the analysis, the researcher should ensure that the research

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[1059] Ibid.
[1060] Ibid.
[1061] Ibid.
[1062] Ibid.
[1063] Ibid.
[1064] Ibid.
[1065] Plamondon, Bottorff & Cole op cit note 1006 at 2.
[1066] Ibid.
[1067] Ibid.
[1068] Ibid.
[1069] JN Lavis, JA Boyko & FP Gauvin 'Evaluating deliberative dialogues focussed on healthy public policy' (2014) *BMC Public Health* 14(1287) 1–7 at 1.
[1070] Ibid at 2.

findings are *trustworthy,* to enhance confidence in the acceptance and utility of the research outcome by various stakeholders.[1071]

Tracy outlines eight key criteria to ensure optimal quality research, in which the research should consist of a "(a) worthy topic, (b) rich rigor, (c) sincerity, (d) credibility, (e) resonance, (f) significant contribution, (g) ethics, and (h) meaningful coherence."[1072] Although each of the above criteria holds significance in deliberation data analysis, emphasis should be placed on *credibility* which pertains to the integrity and *trustworthiness* of the research findings.[1073] This study has decided to follow the standardised criteria for *trustworthiness* as proposed by Lincoln and Guba, which not only incorporates the element of credibility, but dependability, transferability and confirmability, equivalent to reliability and validity in quantitative analysis.[1074] Moreover, considering the characteristics of DPE data mentioned above, Plamondon, Bottorff and Cole suggest that qualitative analyses of DPE data should be guided by a balance between *analytic* and *interpretive strategies* to ensure that the research outcome is not only credible or trustworthy, but adheres to DPE standards such as inclusivity and active participation.[1075] Therefore, to uphold trustworthiness in the research outcome, the analysis in the study was not only guided by Lincoln and Guba's trustworthiness criteria, but the analytical framework proposed by Plamondon, Bottorff and Cole.[1076] These concepts are discussed below; however, the steps followed by the researcher in attaining trustworthiness will be discussed in the data analysis section.

*(a) Trustworthiness*

*(i) Credibility*

Qualitative data analysis is often marked as a 'creative process', raising doubts about credibility.[1077] This stems from its perceived lack of a technical framework or adherence to rules and formulas as observed in quantitative research.[1078] However, said creative methods have the potential to transcend conventional techniques employed in statistical analysis.[1079]

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[1071] Nowell et al op cit note 250  at 982.
[1072] Plamondon, Bottorff & Cole op cit note 1006 at 3.
[1073] Ibid.
[1074] Nowell et al op cit note 250 at 3.
[1075] Plamondon, Bottorff & Cole op cit note 1006 at 3.
[1076] Nowell et al op cit note 250 at 3; Plamondon, Bottorff & Cole ibid.
[1077] MQ Patton, 'Enhancing the quality and credibility of qualitative analysis' (1999) 34(5) *Health services research* 1189–1208 at 1190.
[1078] Ibid.
[1079] Ibid.

Moreover, despite its creative aspect, this form of analysis inherently relies on an astute identification of patterns, where the researcher, whilst immersed in a particular issue, may unexpectedly observe a pattern relevant to a novel issue.[1080] As such, this process is not purely serendipitous, where Pasteur argues that prepared minds are more likely to encounter favourable chances.[1081] Additionally, apart from the creativity and preparation of the researcher, qualitative analysis maintains a technical rigour that is 'analytically rigorous, mentally replicable, and explicitly systematic', able to function alongside its creative dimensions and still meet credibility concerns.[1082] Credibility refers to the 'trustworthiness, verisimilitude, and plausibility of the research findings', indicating the level of accuracy between the research findings and the participants' versions of their experiences.[1083] Accordingly, it is incumbent on the researcher to show and not tell the meaning within the data, where implicit knowledge is also expounded on.[1084] This ensures that the researcher's interpretations are plausible and convincing.[1085]

*(ii) Dependability*

Dependability is concerned with the transparency of the research process or *decision trails* followed by the researcher.[1086] It is attained when the research process is rational, well-documented and can be traced by another researcher, who is able to draw similar conclusions when utilising a comparable study sample under similar conditions.[1087]

*(iii) Transferability*

Transferability involves the external validity of the research outcome, assessing its relevance and applicability in a different setting.[1088] The research outcome becomes transferable when it holds relevance and is relatable to a group of people beyond the study participants.[1089] Thus, it is imperative that the researcher furnishes sufficient details on the study participants and the context of the research to examine the transferability of the findings.[1090]

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[1080] Ibid at 1191

[1081] Ibid.

[1082] Ibid.

[1083] Plamondon, Bottorff & Cole op cit note 1006 at 3; M Sendze 'Case Study of Public Library Directors' Entrepreneurial Leadership Behaviors on Organizational Innovation' (published doctoral thesis, Grand Canyon University, 2019) at 135; Nowell et al op cit note 250 at 3.

[1084] Plamondon, Bottorff & Cole ibid at 3.

[1085] Ibid.

[1086] Sendze op cit note 1083 at 137.

[1087] Nowell et al op cit note 250 at 3; Sendze ibid at 137.

[1088] Sendze ibid at 136; Nowell et al ibid at 3.

[1089] Sendze ibid at 136.

[1090] Ibid at 137.

### *(iv) Confirmability*

Guba and Lincoln provide that confirmability is achieved upon meeting the criteria of credibility, dependability and transferability.[1091] Confirmability refers to the degree to which the research outcome is grounded in the data.[1092] Accordingly, there should be a clear indication that the researcher's interpretations and conclusions have been obtained from the data, where the researcher should account for his/her analytical or theoretical decisions or methods.[1093]

### *(b) Trustworthiness and DPE data*

### *(i) Analytic strategies*

In qualitative research, analytic strategies are adopted to either *categorise* or *connect* data.[1094] Categorising strategies involve the grouping or coding of data according to shared characteristics or similarity.[1095] On the other hand, connecting strategies focus on the examination of context or contextual relationships within the data.[1096] The use of categorisation strategies in isolation have faced criticism for neglecting the *contextual aspects* of the data, which is crucial when dealing with health systems that are profoundly situated, and when conducting action-oriented research that aims to influence health policy developments.[1097] Moreover, confining the data to specific categories leads to data fragmentation or breaking of the overall narrative of the data.[1098] Thus, these strategies (categorising and connecting) should be used in tandem to provide a comprehensive approach to deliberation data analysis.[1099] Plamondon, Bottorff and Cole explore the prospects of merging these strategies in deliberation data analysis, highlighting the importance of achieving balance between two essential aspects: data reduction and distillation (using categorising strategies); and data situatedness, or positioning the data within its broader context to elucidate connections (using connecting strategies).[1100]

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[1091] Nowell et al op cit note 250 at 3.
[1092] Ibid.
[1093] Ibid.
[1094] Plamondon, Bottorff & Cole ibid at 3.
[1095] Ibid.
[1096] Ibid.
[1097] Ibid.
[1098] Ibid.
[1099] Ibid.
[1100] Ibid.

Interestingly, data reduction (categorisation) begins during the deliberation phase, as participants collectively analyse and interpret information or research evidence.[1101] Within these discussions, the initial data may be reduced and refined, revealing core concepts and principal themes within the data.[1102] In this way, the participants actively participate in categorising the data by influencing the generated codes and themes in the data analysis.[1103] These discussions may not only generate said codes but further provide definitions to broad codes, aiding the analysis phase.[1104] During deliberative discussions, participants may also utilise small stories or metaphors to share experiences, convey meaning and foster shared understandings of complex concepts.[1105] These stories or metaphors may be jointly considered, altered or validated during the deliberative discussions.[1106] Thus, enabling avenues for critical thinking, often leading to transformative outcomes.[1107] The use of story-telling is instrumental in providing context and facilitating agreement on priorities, context, calls for action, or decisions.[1108] Additionally, said narratives prove beneficial when determining how to approach deliberation data, providing guidance on how complex matters or ambiguous concepts ought to be interpreted, enhancing the coding framework in the analysis.[1109] The use of story-telling is instrumental in providing context and facilitating agreement on priorities, context, calls for action, or decisions.[1110] Additionally, said narratives prove beneficial when determining how to approach deliberation data, providing guidance on how complex matters or ambiguous concepts ought to be interpreted, thus enhancing the coding framework in the analysis.[1111]

### *(ii) Interpretive strategies*

Interpretation or hermeneutics is central to qualitative research.[1112] It entails any activity that examines textual content to extract meaning.[1113] Ricoeur proposes two forms of hermeneutics, namely, ‘hermeneutics of empathy’ and ‘hermeneutics of suspicion’.[1114] The former adopts a

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[1101] Ibid.
[1102] Ibid.
[1103] Ibid.
[1104] Ibid.
[1105] Ibid at 3, 4.
[1106] Ibid at 4.
[1107] Ibid.
[1108] Ibid.
[1109] Ibid.
[1110] Ibid.
[1111] Ibid.
[1112] C Willig ‘Interpretation in Qualitative Research’ in C Willig & WS Rogers (ed) *The SAGE Handbook of Qualitative Research in Psychology* 2 ed (2017) 274–288 at 274.
[1113] Ibid at 275.
[1114] Ibid at 275–276.

bottom-up approach, focusing on the explicit, surface-level meaning of the textual content,[1115] while the latter seeks to unveil the meaning beneath the text, using a top-down approach.[1116] Willig views these strategies as opposing extremes along the interpretive spectrum, demonstrating two lenses in qualitative interpretation.[1117]

The 'empathetic lens' aims to elucidate and expand on the meaning presented by the text (manifest content), instead of focusing on its underlying content.[1118] As such, this strategy associates itself with the *how* instead of the *why* of experiencing or displaying things.[1119] In this way, the researcher is granted the role of 'facilitator' or 'collaborator' within the interpretation procedure, working jointly with the participants to produce meaning.[1120] Conversely, the researcher may be concerned with the text's underlying or 'latent' meaning, adopting a 'suspicious lens'.[1121] The suspicious lens, in attempting to answer the *why* question, may be used to uncover concealed meanings within textual content by interpreting its surface-level meaning or manifest content.[1122] Thus, the text's manifest meaning only becomes significant as an indicator of its latent meaning.[1123]

The adoption of an empathetic lens appears to align well with DPE objectives.[1124] However, relying solely on this approach may result in the researcher overlooking crucial insights or implicit data, constraining the analysis to surface-level meanings.[1125] Moreover, considering that interpretation is inherently subjective, it is significant to acknowledge the impossibility of 'absolute knowing'.[1126] On the other hand, employing a suspicious lens alone has been critiqued in relation to power dynamics, where the researcher is viewed as an 'expert interpreter' with specialised insights or knowledge on the subject matter.[1127] Furthermore, although these interpretive strategies appear on two opposing ends, Ricoeur did not advocate for the selection of one in lieu of the other, emphasising how they offer distinct insights in data interpretation.[1128] As such, these approaches would serve greater benefit if used together, with

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[1115] Ibid at 276.
[1116] Ibid.
[1117] Plamondon, Bottorff & Cole op cit note 1006 at 5.
[1118] Ibid; Willig op cit note 1112 at 276.
[1119] Willig ibid at 276.
[1120] Plamondon, Bottorff & Cole op cit note 1006 at 5.
[1121] Ibid.
[1122] Ibid; Willig op cit note 1112 at 276.
[1123] Willig ibid at 276.
[1124] Plamondon, Bottorff & Cole op cit note 1006 at 5.
[1125] Ibid.
[1126] Ibid.
[1127] Ibid; Willig op cit note 1112 at 276.
[1128] Willig ibid at 276.

one generating understanding (empathetic lens), and the other formulating reasoning (suspicious lens).[1129] Therefore, achieving a balanced approach between both lenses is crucial for a well-rounded analysis of deliberation data.[1130]

Accordingly, in conducting the thematic analysis, the researcher was guided by the aforementioned framework to uphold trustworthiness and adhere to DPE requirements (such as 'inclusivity and participation') in producing the research outcome.[1131]

## IV DATA ANALYSIS PROCEDURE

The process of data analysis occurs progressively and iteratively in qualitative research, commencing as early as the data collection phase.[1132] This is because preliminary analysis findings may shape or inform ongoing data collection efforts.[1133] These results are particularly useful when refining and selecting relevant data, moreover allowing for early interpretations and conceptualising of the findings.[1134]

In Brink's observation, the main objective of data analysis is to enable greater understanding of the data by reducing and synthesising its content, thereby enabling one to make generalisations about the wider population.[1135] Once the data analysis has been executed, the purpose of interpretation is to derive meaningful conclusions, make informed judgements or provide recommendations based on the research findings.[1136] As this dissertation primarily focuses on the data analysis phase, this section explores how the data analysis has been executed using a thematic qualitative analysis methodology as set out by Braun and Clarke.[1137]

### *(a) Thematic analysis*

In the study, the transcripts were analysed with the aid of Atlas.ti analysis software to conduct a thematic qualitative analysis, which was instrumental in identifying and reporting overarching themes within the data.[1138]

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[1129] Ibid.

[1130] Plamondon, Bottorff & Cole op cit note 1006 at 5.

[1131] Ibid.

[1132] AR Tsanwani 'Tracing factors that facilitate achievement in mathematics in traditionally disadvantaged secondary schools' (published doctoral thesis, University of Pretoria, 2009) at 76.

[1133] Ibid.

[1134] Ibid

[1135] Ibid at 66.

[1136] Ibid.

[1137] Braun & Clarke op cit note 216 at 4.

[1138] Ibid at 6.

Although there are numerous ways of conducting a thematic analysis, Terry et al highlight two fundamental methods:[1139]

(1) The first method is characterised by its focus on 'coding reliability', aligning more with scientific inquiry;[1140]

(2) The second method allows for greater flexibility in the coding and identification of themes, appearing more qualitative in nature.[1141]

Methods that emphasise on coding reliability are typically theory-driven or use deductive coding (themes may be generated using inductive coding in rare occasions) to develop themes or hypotheses (contained in a code book), which are subsequently tested for reliability.[1142] Following a positivist perspective, reliability is dependent on an 'inter-relater coding score' or the extent to which different coders (two or more) concur with the coding outcome, or whether they're able to attain an identical result using the same coding framework (or code book).[1143]

Terry et al criticise this approach, and rightly so, for creating the notion that qualitative coding can and should be objective, reflecting accuracy; for presupposing that the researcher's findings are inherent in the data (although it may not be readily accessible); for creating the idea that the 'researcher subjectivity' is inaccurate or unreliable; and that enhancing the quality of the analysis involves reducing the researcher's subjective influences.[1144]

Additionally, a truly qualitative approach acknowledges that there is no single correct method in conducting the analysis or 'single truth' within the data.[1145] I agree with this position, considering that qualitative research is intrinsically interpretive, and Denzin's argument that 'objective reality will never be captured.[1146] In depth understanding, the use of multiple validities, not a single validity, a commitment to dialogue is sought in any interpretive study'. As such, there may be multiple valid interpretations.[1147] Furthermore, a good 'inter-relater

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[1139] G Terry et al 'Thematic Analysis' in C Willig & WS Rogers (ed) *The SAGE Handbook of Qualitative Research in Psychology* 2 ed (2017) 17–37 at 19.

[1140] Ibid.

[1141] Ibid.

[1142] Ibid.

[1143] Ibid at 19–20.

[1144] Ibid at 20.

[1145] Ibid.

[1146] G Guest, EE Namey & ML Mitchell *Collecting Qualitative Data: A Field Manual for Applied Research* (2013) at 6.

[1147] Ibid.

coding score' does not necessarily indicate coding accuracy but that the researchers share similar coding techniques.[1148]

Given the aforementioned considerations, this study has opted for the second method of thematic analysis (described above), which is theoretically flexible and functions within a purely qualitative framework.[1149] In this approach, researcher subjectivity is crucial in carrying out the procedure, where 'coding reliability' is determined by the degree to which the researcher has engaged with, or immersed in the data.[1150] However, there is no objectively correct or incorrect analysis outcome, where coding reliability will only determine the strength of the analysis.[1151]

### *(i) Rationale*

This study employed the six-phase method for thematic analysis set out by Braun and Clarke.[1152] This method was deemed suitable for several reasons, including its applicability in participatory research, theoretical flexibility, interpretive capacity and ability to analyse extensive data sets.[1153] Unlike analytical methods that require preconceived theoretical expectations, thematic analysis allows the researcher to be receptive to emerging themes and patterns directly from the data, without imposing prior assumptions.[1154] This flexibility permits the adaptation of the analysis to suit research objectives and the theoretical framework of the study.[1155] Moreover, in its interpretive capacity, thematic analysis enables the examination of diverse perspectives, facilitates comparisons (allows the researcher to establish differences or similarities) and has the potential to reveal unexpected or additional insights.[1156] This includes underlying influences on participants' perceptions, thereby paying heed to contextual factors.[1157] Accordingly, it aligns well with participatory research initiatives or studies where the active involvement of the participants is integral in producing the research outcome.[1158]

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[1148] Terry et al op cit note 1139 at 20.
[1149] Ibid.
[1150] Ibid.
[1151] Ibid.
[1152] Braun & Clarke op cit note 216.
[1153] Braun & Clarke ibid at 37; S Williams 'A Critical Realist informed Thematic Analysis: Families' experience of the process of adjustment when a family member is in a forensic mental health hospital' (published doctoral thesis, University of East London, 2018) at 45.
[1154] Williams ibid; Braun & Clarke ibid at 5, 6.
[1155] Nowell et al op cit note 250 at 2.
[1156] Williams op cit note 1153 at 45.
[1157] Ibid at 45, 46.
[1158] Braun & Clarke op cit note 216 at 37.

This method has also been favoured for its simple application, and use in managing and reporting the key elements of *extensive* data sets.[1159]

*(ii) Preliminary considerations*

The researcher had to make three preliminary considerations before proceeding to the analysis phase.[1160] In its flexibility, thematic analysis can be executed under any theoretical or ontological framework, and can be applied across a broad array of research questions.[1161] Moreover, the coding process can be conducted using either inductive or deductive approaches (or both), involving the examination of semantic (manifest) or latent (hidden) content, or both.[1162] Therefore, before conducting the analysis, the researcher had to make the following analytical decisions:[1163]

1) What is the theoretical framework of the analysis?[1164]

2) Will the data be coded using an inductive or deductive approach, or both?[1165]

3) Is the analysis concerned with semantic or latent content, or both?[1166]

To address the first inquiry, the study adopted a critical realist framework to explore the participant's surface-level opinions on HHGE (along with the underlying reasoning for their opinions), and shifts in their opinions over time.[1167] A critical realist epistemology is appropriate when executing 'action-oriented qualitative research' such as this, or research which aims to respond to complex societal issues or influence policy developments.[1168] Critical realism asserts the existence of an objective reality that stands apart from our beliefs, theories and constructed meanings.[1169] This reality cannot be accessed directly, and is often shaped by socio-cultural interpretations and the meaning provided by participants and researchers in accordance with their individual perceptions of reality.[1170] Therefore, to understand why the participant's held their viewpoints and changed their opinions in the study, the researcher was

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[1159] Ibid; Williams op cit note 1153 at 45.
[1160] Williams ibid at 21, 22.
[1161] Ibid.
[1162] Ibid at 22, 23.
[1163] Ibid at 21, 22.
[1164] Ibid.
[1165] Ibid at 22.
[1166] Ibid.
[1167] Ibid at 21.
[1168] Plamondon, Bottorff & Cole op cit note 1006 at 2.
[1169] Ibid.
[1170] Williams op cit note 1153 at 21.

cognisant of the limitations of the data in fully capturing this reality.[1171] The collected data does not grant immediate access to said reality but represents the participants' versions of reality, requiring interpretation to reveal the underlying factors which may influence it.[1172] Furthermore, the analysis reflects the researcher's interpretation, drawing on his/her insights, knowledge and expertise.[1173] Thus, while an objective reality exists, the researcher acknowledged that its true nature is only partially apprehended and can be understood to a limited extent.[1174]

In respect of the second and third inquiry, the study involved both inductive and deductive coding techniques, which allowed for the discovery of emerging patterns and themes, whilst ensuring that the analysis was grounded in the existing theoretical framework.[1175] Moreover, the analysis was concerned with the examination of both semantic and latent content, thus consisting of a hybrid approach to ensure a more holistic understanding of the data.[1176] This was also consistent with the interpretive strategies suggested by Plamondon, Bottorff and Cole, necessitating a balance between an empathetic and suspicious lens of inquiry.[1177]

### *(iii) Six-phase data analysis procedure*

The process of thematic analysis, as outlined by Braun and Clarke, begins the moment the researcher observes and seeks meaningful patterns and potential issues in the data, often initiated before the actual analysis is conducted.[1178] This process culminates with the reporting of the identified themes and issues.[1179] According to Braun and Clarke's six-phase analysis (illustrated in figure 1), the following steps should be taken when conducting a thematic analysis:[1180]

1) Familiarisation with the data;[1181]

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[1171] Ibid.
[1172] S Williams op cit note 1153 at 44.
[1173] Ibid.
[1174] S Williams op cit note 1153 at 44.
[1175] Linneberg & Korsgaard op cit note 228 at 14; Williams op cit note 1153 at 22.
[1176] Terry ibid.
[1177] Plamondon, Bottorff & Cole op cit note 1006 at 5.
[1178] Braun & Clarke op cit note 216 at 15.
[1179] Ibid.
[1180] Ibid at 35.
[1181] Ibid at 16.

2) The production of initial codes;[1182]

3) Identifying themes;[1183]

4) Reviewing the identified themes;[1184]

5) Defining and labelling the themes;[1185]

6) Writing the report.[1186]

*Familiarisation with the data*

The first phase was initiated by the researcher becoming familiar with and immersed in the data set, which involved a repetitive and active reading of the data to identify possible patterns, meanings, similarities, etc, therefore employing *categorising* strategies.[1187] The research aims and preliminary considerations (as referred to earlier) were significant in deciding how the reading process ought to occur.[1188] In this phase, it was important to ensure an adequate understanding of the 'depth and breadth' of the data before proceeding to the coding phase,[1189] thus the researcher read through the complete data set more than once to understand the various dimensions of the data.[1190] Whilst immersing in the data, the researcher took down notes and highlighted key ideas, such which became very useful during coding and generating themes.[1191] Since the study dealt with verbal data, the process of *transcription* was also advantageous in becoming more acquainted with the data set, in which some scholars contend that it should be regarded as a pivotal stage in data interpretation.[1192]

*The production of initial codes*

Once the researcher became familiar with the data and had recorded its key aspects, the coding phase had commenced.[1193] In this phase, the researcher produced initial codes, which were

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[1182] Ibid at 18.
[1183] Ibid at 19.
[1184] Ibid at 20.
[1185] Ibid at 22.
[1186] Ibid at 23.
[1187] Ibid at 16; Plamondon, Bottorff & Cole op cit note 1006 at 3.
[1188] Braun & Clarke ibid at 16.
[1189] Ibid.
[1190] Ibid.
[1191] Ibid at 17.
[1192] Ibid.
[1193] Ibid at 18.

semantic or latent segments or features within the data that captured his/her interest.[1194] These may take the form of simple or basic elements that encapsulate an idea or meaningful concept in relation to the research questions.[1195] After the codes were established, the researcher ensured that every relevant data extract was appropriately coded or assigned the code it represented, and then subsequently grouped under each respective code.[1196] However, there was a possibility that certain extracts would remain uncoded, subject to a single code, or be coded multiple times under a number of themes.[1197] Throughout this phase, the researcher remained encouraged to embrace exploration, coding for numerous potential themes that may prove beneficial in subsequent phases.[1198] Furthermore, the coded extracts retained some of its surrounding text to preserve the context, and to address the frequent critique that coding may overlook the broader context of the data.[1199] This allowed the researcher to consider contextual relationships, which was significant in the interpretation of the data (connecting strategies).[1200] The data underwent manual coding before being imported into Atlas.ti data analysis software to validate the coding structure.[1201]

*Identifying themes*

This phase focused on the 'units of analysis' or the overarching themes in the data set.[1202] The concept of *theme* is defined as the prevalence of a significant aspect in the data, which may be useful in providing meaning or answering the research questions.[1203] Accordingly, after the *initial codes* were produced and listed, they were analysed to determine how they could be grouped into candidate themes (along with their corresponded data extracts).[1204] Thus, in this phase, the researcher established connections or relations between the individual codes, themes and potential sub-themes.[1205] In effect, some codes had created core themes or formed sub-themes, whilst some were dismissed or did not fit into any of the identified themes (forming a 'miscellaneous' theme).[1206]

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[1194] Ibid.
[1195] Ibid.
[1196] Ibid at 18, 19.
[1197] Ibid at 19.
[1198] Ibid.
[1199] Ibid.
[1200] Plamondon, Bottorff & Cole op cit note 1006 at 3.
[1201] Braun & Clarke op cit note 216 at 18.
[1202] Ibid at 18, 19.
[1203] Ibid at 10.
[1204] Ibid at 19.
[1205] Ibid at 20.
[1206] Ibid.

*Reviewing the identified themes*

In this phase, the candidate themes endured a process of review and refinement, which took place under two stages.[1207] To illustrate, some themes had merged into a single overarching theme, while others were separated into individual themes.[1208] Simultaneously, certain themes were no longer considered as themes.[1209] During this phase, it was important that the themes exhibited 'internal homogeneity' or were meaningfully related, and 'external heterogeneity', where it was evident that distinct differences existed between them.[1210] The first stage of the review involved examining the 'coded data extracts'.[1211] Accordingly, the researcher conducted a meticulous reading of the compiled data extracts within each theme to determine whether they demonstrated a coherent and logical pattern.[1212] If not, it meant that the themes were problematic or the data extracts did not fit under a certain theme.[1213] In this case, the researcher either revised or refined the theme, or the data extracts were placed under a different theme or removed.[1214] This ensured that the themes had accurately and sufficiently reflected the coded data.[1215] The researcher then presented the candidate themes in a 'thematic map'.[1216]

In the second stage of the review, the 'entire data set' was examined to determine if the candidate themes were valid, or provided a true representation of the data set.[1217] This process of re-reading the complete data set also allowed the researcher to identify any data that was not coded or put into a theme, for potential re-coding.[1218] During this phase of the analysis, the researcher addressed several critical concerns such as, (a) are the themes logical and suitable in the context of the data?; (b) is there substantial support for the themes within the data?; (c) does the thematic map contain themes that are overly broad and complex, lacking specificity?; (d) are there any overlapping themes, if so, should they be combined into a single theme?; (e) can any subthemes be developed?; and (f) are there additional themes latent within the data?[1219] In light of the above questions, the thematic map was often modified and refined until it

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[1207] Ibid.
[1208] Ibid.
[1209] Ibid.
[1210] Ibid.
[1211] Ibid.
[1212] Ibid.
[1213] Ibid.
[1214] Ibid at 20, 21.
[1215] Ibid at 21.
[1216] Ibid.
[1217] Ibid.
[1218] Ibid.
[1219] Sendze op cit note 1083 at 146.

accurately represented the patterns and meanings present within the data.[1220] This phase allowed the researcher to gain insight into the various themes existent in the data, their interconnections, and how they contribute to the overall narrative of the data.[1221]

### *Defining and labelling the themes*

This phase included defining and conducting a final revision of the themes to demonstrate their fundamental meanings and core characteristics.[1222] The researcher begun by analysing each theme and their coded extracts to capture the story that each were conveying.[1223] Moreover, to establish how this story aligns with the narrative of the entire data set, considering the research questions.[1224] The objective was to discover the relationship between the different themes (and subthemes), together with the general narrative of the data to ensure that the themes remained distinctive and did not excessively overlap.[1225] The researcher revisited the coded extracts of each theme to identify its core meaning or central concept, and what it encapsulates about the data.[1226] At the conclusion, it was imperative for the researcher to have established clear and precise definitions for each theme, delineating their scope and boundaries.[1227] Furthermore, while provisional titles may have been initially assigned to each theme, the researcher had to consider the final names for them, ensuring they were succinct, impactful, and immediately reflective of the essence of each theme.[1228]

### *Writing the report*

In the final phase, the researcher executed a concluding analysis and compiled a report detailing the overarching narrative presented by the data.[1229] This involved highlighting key themes that directly responded to the research questions, supported by pertinent extracts illustrating the frequency of such themes.[1230] These extracts were carefully selected to vividly exemplify the core concept of each theme.[1231] Moreover, the report aimed to present a succinct, coherent, and

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[1220] Braun & Clarke op cit note 216 at 21.
[1221] Ibid.
[1222] Sendze op cit note 1083 at 146.
[1223] Braun & Clarke op cit note 216 at 22.
[1224] Ibid.
[1225] Ibid.
[1226] Ibid.
[1227] Ibid.
[1228] Ibid at 22, 23.
[1229] Ibid at 23.
[1230] Ibid.
[1231] Ibid.

engaging narrative of the data across the themes, avoiding unnecessary repetition.[1232] Rather than solely providing examples or extracts, the report also offered an analytical perspective on the data's narrative, framing it within the context of the research questions.[1233] This analytical approach ensured that the interpretation of the data transcended mere description, presenting arguments rooted in the research objectives.[1234] By doing so, the researcher ensured that the narrative was compelling and demonstrated the validity and significance of the analysis.[1235]

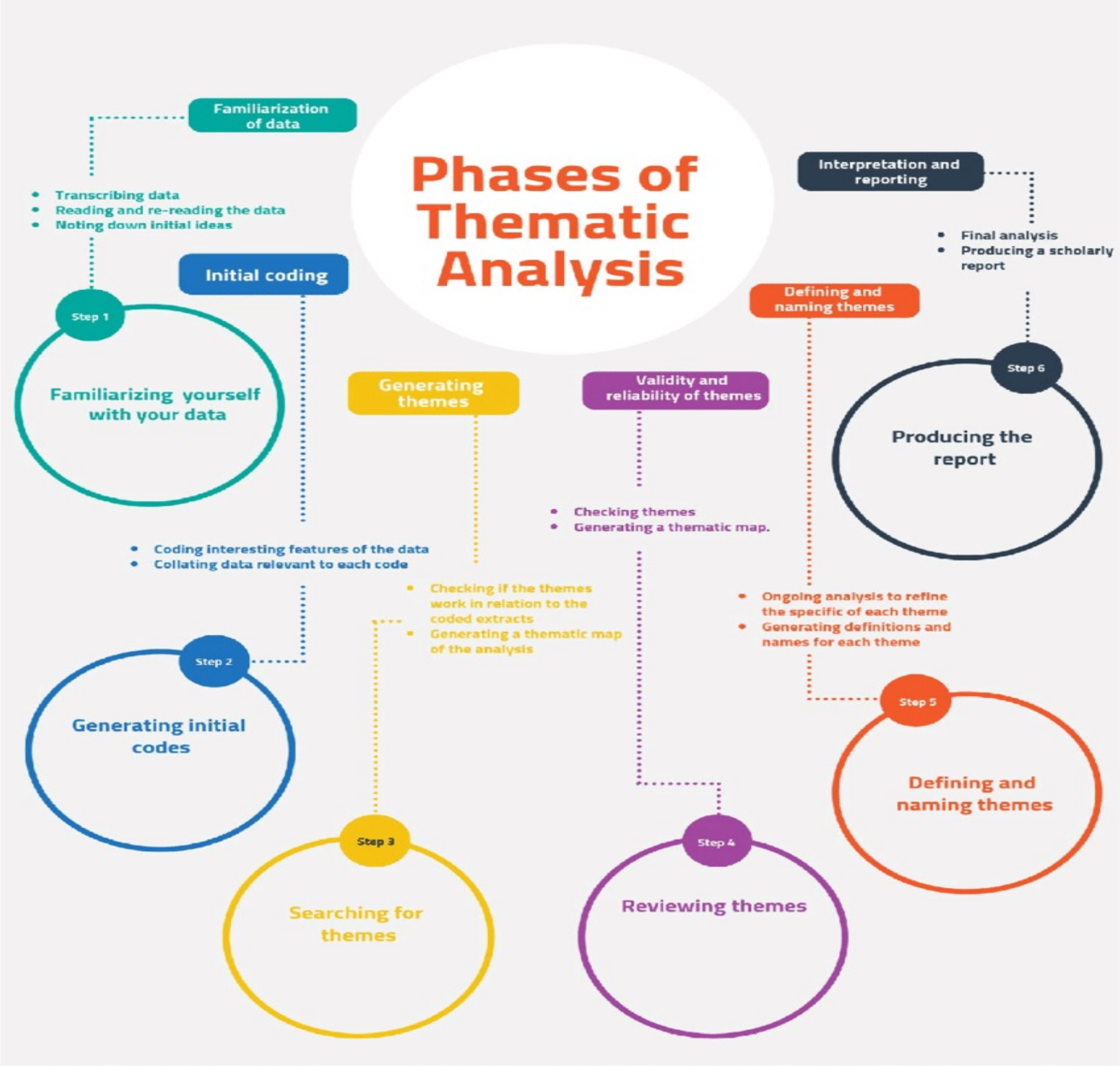

Figure 1: Braun and Clarke's six-phase thematic analysis[1236]

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[1232] Ibid.
[1233] Ibid.
[1234] Ibid.
[1235] Ibid.
[1236] Taken from Sendze op cit note 1083 at 148.

### *(b) Trustworthiness and ethical standards*

The researcher implemented a series of measures to assure trustworthiness in the study outcome. In order to achieve Lincoln and Guba's *trustworthiness* criteria, the analysis followed the guidelines outlined by Nowell et al for conducting a trustworthy thematic analysis.[1237] To establish *credibility*, the analysis was not only guided by the analytic and interpretive strategies provided by Plamondon, Bottorff and Cole discussed earlier, but also incorporated bracketing and peer debriefing.[1238] For example, the researcher enabled an unbiased examination of the data by bracketing or setting aside pre-existing ideas or assumptions.[1239] Additionally, to maintain rigor and ensure logical decision-making, the researcher sought an external perspective by discussing the analysis and interpretations with a peer who was well-versed in the research topic.[1240] Credibility was further increased through 'prolonged engagement' with the data.[1241] *Dependability* was enhanced by recording all methodological and theoretical decisions taken during the analysis with reasoning, thus keeping an audit trail.[1242] The researcher enabled the assessment of *transferability* (of the research outcome) by providing sufficient details on the research participants and context.[1243] Lastly, although *confirmability* was reached upon achieving the abovementioned criteria (credibility, dependability and transferability), it was heightened by disclosing how decisions (such as the coding structure, identified themes, etc), interpretations and conclusions were grounded in the data, using coded data extracts to provide evidence.[1244]

In addition, the study was guided by the analytical and interpretive strategies proposed by Plamondon, Bottorff, and Cole.[1245] To elucidate, data grouping on the basis of similarity enabled the identification of themes, in which careful consideration was also given to the context of the data to enhance interpretation.[1246] In this way, the researcher achieved balance between categorising and connecting strategies.[1247] The analysis was also concerned with

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[1237] Nowell et al op cit note 250 at 3.
[1238] Plamondon, Bottorff & Cole op cit note 1006 at 2; Sendze op cit note 1083 at 136.
[1239] Sendze ibid at 136.
[1240] Sendze ibid at 136; Nowell et al op cit note 250 at 3.
[1241] Nowell et al ibid at 3.
[1242] Nowell et al ibid; Sendze op cit note 1083 at 137.
[1243] Sendze ibid at 137; Nowell et al ibid at 3.
[1244] Nowell et al ibid; Sendze ibid at 138.
[1245] Plamondon, Bottorff & Cole op cit note 1006 at 3.
[1246] Braun & Clarke op cit note 216; Plamondon, Bottorff & Cole ibid at 3.
[1247] Plamondon, Bottorff & Cole ibid.

surface-level and underlying meanings in the data (semantic and latent content) to answer the research questions.[1248] Thus, adopting an empathetic and suspicious lens.[1249]

To maintain ethical standards in the analysis, ethical clearance was acquired from the ethics committee of the University of KwaZulu-Natal, namely, the Humanities and Social Sciences Research Ethics Committee prior to commencing the study.[1250] Participation in the study was contingent on voluntary engagement and informed consent received from the participants.[1251] Thereafter, in order to be eligible for the study, the participants had to demonstrate (among others) their willingness to engage in a recorded discussion for research objectives, through an online questionnaire.[1252] Confidentiality was ensured by removing the names of the participants and issuing a respondent number to each participant before transcribing the raw data (audio files) and carrying out the analysis.[1253] After the transcription phase, the raw data were secured in a cloud-based folder, in which the principal investigator (supervisor of the dissertation) has sole access.[1254]

### *(c) Limitations of the analysis methodology*

It was crucial for the researcher to be mindful of the potential limitations of the analysis methodology before engaging in the data analysis process.[1255] Thus, while thematic analysis had offered a valuable means of the examining data, this methodology was not without challenges.[1256] The first limitation stems from the absence of sufficient literature and theory on thematic analysis, creating uncertainty for executing a thematic analysis with precision.[1257] This deficiency is attributed to the fact that thematic analysis lacks clear definition and a theoretical underpinning.[1258] Moreover, it has not gained prestige as a distinctive analysis methodology but as a mere tool in conducting analyses.[1259] On the contrary, Braun and Clarke have claimed its existence as a distinct methodology, as mentioned earlier.[1260] Moreover,

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[1248] Williams op cit note 1153 at 22.
[1249] Plamondon, Bottorff & Cole op cit note 1006 at 5.
[1250] D Thaldar et al op cit note 92 at 6; Sendze ibid at 149.
[1251] Thaldar et al ibid at 6.
[1252] Ibid.
[1253] Sendze op cit note 1083 at 128.
[1254] Ibid at 145.
[1255] Braun & Clarke op cit note 216 at 27.
[1256] Ibid.
[1257] Nowell et al op cit note 250 at 2.
[1258] Ibid; Braun & Clarke op cit note 216 at 5, 6.
[1259] Braun & Clarke ibid at 28; Williams op cit note 1153 at 34.
[1260] Braun & Clarke ibid at 4.

despite this limitation, such theoretical flexibility proved advantageous in the study.[1261] It was easily adaptable to meet the study's research framework and questions.[1262] It also allowed the researcher to approach the data from various angles, effectively addressing the research questions.[1263] Notably, this quality rendered thematic analysis user-friendly, particularly for the novice researcher who did not require advanced skills to conduct the analysis rigorously as required in for example, discourse analysis.[1264]

A second limitation concerned the flexibility of thematic analysis, which enables the researcher to interpret and analyse the data in various ways, potentially generating a substantial amount of themes.[1265] This introduces challenges in relation to consistency and coherence when conducting the analysis.[1266] Furthermore, its interpretative capacity may be restricted if the analysis is not situated within an established theoretical framework.[1267]Accordingly, to avoid this dilemma, the researcher adopted a hybrid coding approach, integrating both inductive and deductive coding techniques, where the researcher maintained balance between being open to emerging themes, while preserving a structured and theoretically grounded analytical process.[1268] The analysis was also conducted under a critical realist theoretical framework (discussed earlier) to avoid restrictions on interpretation.[1269]

Lastly, thematic analysis cannot be utilised to judge the use of language in the data as would be possible with discourse analysis.[1270] However, this analysis was not concerned with the language structure or the role of language in conveying meaning, but to merely understand why the participants held certain perspectives and changed their opinions during the study.[1271]

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[1261] Ibid at 5.

[1262] Ibid; Nowell et al op cit note 250 at 2.

[1263] Nowell et al ibid at 2.

[1264] Ibid; Braun & Clarke op cit note 216 at 28, 37.

[1265] Braun & Clarke ibid at 27, Nowell et al op cit note 250 at 2.

[1266] Nowell et al ibid at 2.

[1267] Braun & Clarke op cit note 216 at 27.

[1268] Linneberg & Korsgaard op cit note 228 at 14; Williams op cit note 1139at 22.

[1269] Terry ibid at 21.

[1270] Braun & Clarke ibid at 28.

[1271] N van Han 'Contrast and critique of two approaches to discourse analysis: Conversation analysis and speech act theory' (2014) 5(4) *Advances in Language and Literary Studies* 155–162 at 155.

# *CHAPTER 4*

# *DPE STUDY ON HHGE IN SOUTH AFRICA: RESULTS*

## I INTRODUCTION

The deployment of genetic engineering technologies for the alteration of human germline cells has stimulated broad public debate despite its potential to revolutionise medicine.[1272] Aside from concerns pertaining to the safety and effectiveness of the technology, numerous ethical and social questions have been raised, necessitating public involvement before the development of national and global regulatory frameworks for HHGE can be sought. [1273] Notwithstanding the imperative for public participation and the various calls for 'extensive social dialogue', this topic has been reserved for experts with insignificant attempts at public engagement.[1274] The inclusion of the general public in this debate is integral in defining the parameters of acceptable use of this technology considering the ethical and social dilemmas, and averting public disapproval when it becomes accessible.[1275] As argued by Carpenter, the concept of legitimacy includes a significant subjective aspect, extending beyond the requirement of legal validity.[1276] This includes moral authority or acceptance of the validity of a law by its subjects.[1277] Although public acceptance does not hold legal authority, the enactment of public policy which does not align with societal values or integrate public concerns could prompt resistance and undermine public trust and the legitimacy of legal policies. [1278]

Given this impetus, the purpose of this study was to integrate public perspectives with scientific innovations such as CRISPR-Cas9, to compile research which may be useful to policymakers for the future regulation of HHGE in South Africa. Thus, through extensive deliberations with the informed public across three evenings, we attempted to dissect the South African perspective on HHGE.[1279] This included the ethical and social arguments raised by the

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[1272] International Academies of Science, Medicine and Engineering op cit note 5.
[1273] Van Baalen et al op cit note 4 at 3.
[1274] Ibid.
[1275] Litis, Hoover & Matthews op cit note 1 at 2.
[1276] G Carpenter 'Public opinion, the judiciary and legitimacy' (1996) 11(1) *SA Publiekreg= SA Public Law* 110–122 at 111.
[1277] Ibid.
[1278] Litis, Hoover & Matthews op cit note 1 at 3.
[1279] Thaldar et al op cit note 75.

informed public on prospective HHGE applications for serious heritable diseases, immunity and genetic enhancements.[1280] Whilst it was emphatic in *S v Makwanyane* that public opinion does not carry substantial weight in judicial decisions, Mahomed J emphasised its vital and, at times, 'decisive' role in legislative decisions.[1281] Thus, the results of the study may be advantageous to policymakers as evidence-based research for the future regulation of HHGE in South Africa.[1282]

The preceding chapter demonstrated the nature and process of the thematic qualitative analysis methodology employed in the study. In this chapter, I present the results of the analysis. However, before advancing to the research outcome, I discuss the research parameters which describe the study sample, research setting, method of data collection and nature of the analysed data. Accordingly, this chapter is divided into two sections, namely, (i) Research parameters and (ii) Results.

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[1280] Ibid at 7, 8.

[1281] Carpenter op cit note 5 at 112.

[1282] Lavis, Boyko & Gauvin op cit note 1069 at 1–2.

## II RESEARCH PARAMETERS

### (*a*) *Sample size and eligibility requirements*

The sample pool was restricted to 30 South African citizens, recruited based on differing demographics (such as age, gender, education and religious background).[1283] The recruitment of a small sample was consistent with the literature and the objective of the study to ensure inclusivity through diversity.[1284] Accordingly, the researchers did not intend on capturing a sample that was statistically representative of the South African population, but a stratified sample which included people from diverse backgrounds.[1285] This broadened the scope of perspectives received on HHGE, enabling viewpoints from diverse angles.[1286] Moreover, reducing bias in the recruitment process.[1287] As such, selecting a small, uneven group of approximately 25 participants was deemed suitable, however, 30 participants were recruited to accommodate possible attrition during the study.[1288] Notably, there was minimal attrition, which had only a minor impact on the study findings.[1289] To illustrate, two participants were unable to attend on specific evenings of the deliberations (one participant on the first evening and the other on the third) due to power outages that are prevalent in South Africa.[1290] Furthermore, another Participant opted out of the study just before it began.[1291] The sample pool was then reduced to 29.[1292]

In order to be eligible for the study, it was necessary that each candidate exhibited proficiency in the English language, both in verbal communication and written expression.[1293] The candidates were also required to: (a) hold South African citizenship; (b) be 18 years or older (majority); (c) demonstrate a willingness to be educated on genome editing and the ethical issues raised; (d) show a willingness to independently formulate opinions based on the diverse applications of genome editing, and to share those opinions with the other participants; (e) be open to participating in an online discussion across three evenings that will be recorded for further research; and (f) have adequate access to the internet and the Zoom application.[1294] The

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[1283] Thaldar et al op cit note 92 at 6.
[1284] Thaldar et al op cit note 75 at 3, 4.
[1285] Ibid.
[1286] Ibid at 4.
[1287] Ibid.
[1288] Ibid at 3, 6.
[1289] Thaldar et al op cit note 92 at 15.
[1290] Ibid
[1291] Ibid at 7.
[1292] Ibid.
[1293] Thaldar et al op cit note 75 at 5.
[1294] Thaldar et al op cit note 92 at 6.

questionnaire also recorded demographic data which was used in the sample selection.[1295] Although demographic data was utilised to recruit a diverse sample pool, this study was not concerned with the effect of said data on opinion formations. Eligible candidates were also required to pass an entrance exam after studying the supplied resource material; and provide informed consent to participate, in order to be included in the research sample pool.[1296]

### *(b) Research setting, data collection and type*

The meetings were conducted online using the Zoom video conferencing application, across three consecutive evenings (during the weekdays).[1297] The meetings were each of a 90-minute duration.[1298] Given the constraints imposed by the COVID-19 pandemic, this study chose to explore the 'Virtual Research Environment' (VRE) in practice of social distancing.[1299] The VRE was increasing in prevalence for academic research during such time in its ability to transform the research domain for academia.[1300] As alluded to in chapter 1, this was the first DPE study on HHGE conducted in South Africa, moreover, using a VRE.[1301] The participants were provided with internet data upon acceptance of the offer, and were required together with their facilitators to keep their videos turned on throughout the deliberations.[1302] This enhanced the personal aspect of the online deliberations, enabling both the facilitators and participants to observe non-verbal actions.[1303] Overall, the online discussions commenced without encountering difficulties or disruptions in relation to internet stability.[1304] Moreover, the online format did not limit the study in any significant way.[1305]

### *(c) Data collection and type*

The research data was gathered from two sources, namely, online opinion polls and the deliberations.[1306] Online opinion polls were conducted one week prior to the deliberations, during the deliberations (at the end of each evening) and one week after the deliberations.[1307]

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[1295] Thaldar et al op cit note 75 at 6.
[1296] Thaldar et al op cit note 92 at 6.
[1297] Thaldar et al op cit note 75 at 5, 9.
[1298] Ibid.
[1299] Ibid at 5.
[1300] Ibid.
[1301] Ibid at 12.
[1302] Thaldar et al op cit note 92 at 9.
[1303] Ibid.
[1304] Ibid.
[1305] For the limitations of the VRE format, refer to Thaldar et al op cit note 75 at 12.
[1306] Ibid at 9, 10.
[1307] Thaldar et al op cit note 92 at 10.

These polls presented 13 policy questions to participants for voting.[1308] The primary data source, however, was the deliberations, which comprised both the breakaway and plenary discussions.[1309] During each evening, the participants were randomly assigned to a breakaway group consisting of five participants, facilitated by expert-trained academics.[1310] Two breakaway sessions were held each evening, each followed by a plenary discussion, resulting in two plenary discussions per evening.[1311] The first breakaway discussion was precisely 25 minutes, during which participants were asked to provide feedback on the policy questions discussed for that particular evening.[1312] The second breakaway discussion was of a 35-minute duration, where the participants were once again randomly assigned to said groups, with the objective of delving deeper into the evening's topic, taking into account the arguments put forward during the plenary discussions.[1313] In the plenary discussions, the representatives for each were responsible for presenting the group's findings, and could seek assistance, if necessary, from other participants in their groups.[1314] The deliberations in the first evening were approximately three hours (with the introductions), whilst the remaining evenings were of a two and a half hour duration.[1315]

The deliberations for each evening were recorded in a video format and subsequently transcribed verbatim by the researcher in font 12 pt Times New Roman, using a single-spaced Word format.[1316] A total of 36 transcripts were generated from the breakaway sessions and compiled into a unified PDF document. The plenary discussions were also consolidated into a single PDF file.

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[1308] Ibid.
[1309] Ibid 9, 10.
[1310] Ibid at 9, 10.
[1311] Ibid at 10.
[1312] Ibid.
[1313] Ibid.
[1314] Ibid.
[1315] Ibid at 9.
[1316] Ibid.

## III RESULTS

Chapter 1 introduced the deliberative outcome of the South African DPE study, offering a brief overview of the South African perspective on HHGE.[1317] This dissertation has opted for a thematic analysis of the study findings to comprehensively explore this perspective. As such, it focuses on *why* the participants held their viewpoints and changed them during the study to derive the South African perspective based on a thematic qualitative analysis. This section presents the results of the study after the deliberation transcripts have been thematically analysed, producing the analytical output of the study.

The study participants were presented with 13 policy proposals divided into three broad topics discussed below:

Topic 1: 'Provided that it is safe and effective, our country's laws should allow parents to choose to use genome editing before a child's birth to–

P1. prevent the child from being born with a serious heritable disease like sickle cell anaemia, muscular dystrophy, or Alzheimer's.
P2. prevent the child from being born with a less serious heritable disease like asthma or eczema.
P3. prevent the child from being born with a disability like deafness or blindness.
P4. prevent the child from being born with albinism.
P5. prevent the child from being born with Down's syndrome.'[1318]

Topic 2**:** 'Provided that it is safe and effective, our country's laws should allow parents to choose to use genome editing before a child's birth to–

P6. make the child immune to contracting a serious disease like TB during the child's life.
P7. make the child immune to contracting a serious but mostly preventable disease like HIV/Aids during the child's life.
P8. make the child immune to contracting Covid-19 during the child's life.
P9. make the child immune to contracting an illness like the flu or a common cold during the child's life.'[1319]

Topic 3: 'Provided that it is safe and effective, our country's laws should allow parents to choose to use genome editing before a child's birth to–

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[1317] As discussed in Thaldar et al ibid.
[1318] Ibid at 8.
[1319] Ibid.

P10. influence talents such as how intelligent or athletic the child will be.
P11. influence personality traits, such as how aggressive or cooperative the child will be.
P12. influence the sexual orientation of the child.
P13. determine aesthetic characteristics, such as the child's skin tone (to be lighter or darker) or the child's eye colour.'[1320]

For each policy proposal, the participants could indicate one of three responses, requiring justification:[1321]

- Yes, always.
- Yes, subject to certain conditions.
- No, never.

The participants' responses were recorded and thematically analysed to answer the key research question: What is the informed South African public perspective on HHGE? To address this question, the thematic analysis was guided by the following sub-research questions:

- SRQ 1: What is the informed South African public perspective on the use of HHGE to prevent genetic health conditions?
- SRQ 2 What is the informed South African public perspective on the use of HHGE to enhance immunity against infectious diseases?
- SRQ 3: What is the informed South African public perspective on the use of HHGE to edit for genetic enhancements?

In addition to this inquiry, the study aimed to understand:

- SRQ 4: Why did the informed South African public change their opinions during the study?

As a result, six principal themes were identified from the data in response to the above research questions.

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[1320] Ibid at 9.
[1321] Ibid.

*(a) Themes*

The overarching theme across the three evenings was: ‘Balancing health benefits (including improvements to the quality of life) with unanticipated risks to individuals and society.’ As such, seven themes emerged from the data, with 13 sub-themes presented in Table 4.1 below.

*Table 4.1: Presentation of themes*

| *Theme* | *Sub-theme* |
|---|---|
| 1. The potential benefits of HHGE | 1a. Benefits for the prospective individual<br>1b. Benefits for society |
| 2. Future implications for natural immune responses | 2a. The potential loss of natural immunity |
| 3. Equitable access to HHGE for everyone | 3a. Financial barriers and active government intervention<br>3b. Governmental challenges in ensuring equitable access |
| 4. HHGE and discrimination in society | 4a. Negative impact on societal acceptance<br>4b. The objective to improve societal well-being |
| 5. The right to autonomy | 5a. The preservation of free will and personal identity<br>5b. Informed consent and future consequences |
| 6. Going against human nature | 6a. Heading down a slippery slope<br>6b. Nature vs Nurture<br>6c. The loss of genetic diversity |
| 7. Ambiguity in reasons for opinion changes | 7a. Inconsistencies between quantitative and qualitative data |

*Theme 1: The potential benefits of HHGE*

Theme 1 highlights the participants' perception of HHGE as a method to correct, treat or prevent potential health problems in prospective individuals, providing numerous health benefits. Notably, the participants recognised the broader impact of using HGE beyond the individual, extending to improve not only the life of prospective parents but also to promote societal well-being. This theme explores how the use of HHGE would confer a benefit not only to the prospective individual but also to society. For the prospective individual, HHGE could be used to prevent or enhance immunity against serious health conditions that are life-threatening, profoundly impact the child's quality of life, and are not always preventable. The severity of the condition surfaced as a pivotal and often decisive factor in determining whether HHGE applications should be permitted.[1322] For society, it could be utilised to alleviate the existing financial burden on public healthcare and improve public health.

*Subtheme 1a. Benefits for the prospective individual*

*(i) Prevention of serious genetic health conditions*

The severity of the condition was given substantial weight when determining the use of HHGE for serious genetic health conditions. As such, some participants agreed to use the technology merely because the severity of the disease would justify its use (Participant 27). On the other hand, other participants weighed severity against the *life-threatening* nature of the disease or its potential to shorten the individual's life, where Participant 25 stated:

> "[W]ith it [genome editing] being used for serious conditions and less serious conditions, I think, um, it's just a question of it being, um, is it life-threatening […] or not? Then […] if it is, I think it should be used. Um, but if the person […] can live with the condition […] it's totally fine."

Alternatively, disease severity was considered in light of its immense impact on the prospective child's *quality of life*, where it could hinder the child's ability to live a normal, good life. As Participant 27 articulated:

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[1322] As corroborated by Thaldar et al ibid at 12.

> "[I]f it is something that is serious and has a large impact on their life, I think to make the quality of their life better, it would be much more simple to edit their genes because they would be able to live their entire life with the correct gene instead of having to suffer […]"

*"Is it Life-threatening?"*

The participants supported the use of HHGE for its potential to prevent conditions which could present a serious life risk to the prospective child, or what they deemed as life-threatening. For some participants, certain conditions were inherently life-threatening, thus warranting the use of the technology. This perspective was frequent with serious heritable diseases (P1), which were often associated with a reduced lifespan owing to their severity. This sentiment was echoed by Participant 29, where he stated that he would use the technology "if it's a very, very serious disease that a normal child is going to struggle probably most of their life […]" When asked to provide examples of what he considered serious, he provided:

> "The ones stated in the questions, like the Alzheimer's, like those type of diseases […] Sickle cell, muscular dystrophy, or like life threatening diseases where the child won't survive."

In a similar vein, Participant 12 expressed: "I would definitely agree for gene editing to be used because this is a life-threatening thing. People can die from it."

For less serious heritable diseases (P2), the participants displayed ambivalence with respect to the severity of the disease, precisely when considering asthma. However, when it came to eczema, most participants felt that it was not a life-threatening condition and could be managed through medical intervention. As Participant 5 stated:

> "[E]czema is not a disease to me. It is something on your skin, it is not life threatening, it will never be life threatening. So, that is not a disease to me […] Eczema won't change my life, I will rub the cream and I will go the dermatologist if I want to improve my life, but [inaudible] asthma could change my life."

In commonality, most participants shared the viewpoint that asthma could manifest in "varying degrees" and may escalate to a significant health problem (Participant 1), despite being treatable. As Participant 27 provided: "[A]sthma could be mild or it could be quite severe, requiring hospitalisation […]"

Some participants interpreted severity as a subjective concept, indicating that the severity of the asthma may differ from person to person, depending on an individual's personal experience. According to Participant 26:

> "[W]hen you say a disease is less serious […] it depends on the experience of a person […] Asthma is a very serious disease, you know, and you, you – it can be manageable, of course, but it's, it's a very serious disease and that goes with the subjective interpretation –, or how the person experiences that disease."

As such, certain cases of asthma may be life-threatening. This point was emphasised by Participant 1, who discussed her personal experiences with people with asthma:

> "I've had a couple of people that passed away from asthma. Sometimes you also get people that, for some reason or other, gets seasonal asthma or asthma when they are older, so just because of the mortality rate that's attached to it, I would still say yes. It could be ultimately as serious as the first question."

She later added: "[Y]our life can be threatened by asthma. I've personally known people that died because of asthma, you get different types of asthma." Thus, she considered the severity of asthma based on her subjective experience, where the potential risk to an individual's life was an important factor, in her opinion.

Severity was a weighty factor in the discussions, where a few participants felt that HHGE could only be permissible if the asthma was severe enough. Drawing on this point, Participant 27 expressed:

> "I feel that even though it is a less serious heritable disease, the severity of the disease needs to be accounted for and if it is possible to have the child that's being born with this disease, especially if the severity is high, then I feel that it would justify the use of genetic editing […] I think that it should be done, but it should be done under certain conditions, like with respect to the severity of the illness."

Conversely, even though severity was an important consideration for the participants, some participants raised doubts about whether the severity of asthma could be determined before using the technology. According to Participant 2:

> “[S]o the conditions for, uh, question number two is, uh, asthma is, you can get mild asthma and very serious asthma. Um, but we do not know yet if we can pinpoint the genes to see if it’s serious asthma or not, and to just kind of prevent that, to not have asthma would be beneficial.”

The participant expressed uncertainty as to whether the genetic technology could accurately identify the genes responsible for severe asthma. However, despite this uncertainty, she advocated for the use of HHGE to remove the risk of developing asthma altogether, given its potential severity.

Some diseases may be life-threatening due to external or environmental factors. To illustrate, although most participants recognised the intrinsic risks associated with severe asthma, Participant 7 highlighted the role of a person’s “living environment” in exacerbating the condition. She pointed out that environmental factors such as pollution or poor air quality could worsen the symptoms of asthma, potentially leading to a life-threatening situation. Moreover, in the context of the COVID-19 pandemic, Participant 19 indicated the increased risk of mortality for individuals with asthma. She added:

> “[S]o asthma […] well, in the context of COVID-19, people with asthma were more likely to die. So there was higher mortality due to having those pre-existing conditions […] Yes, asthma is treatable […] but we don’t know what could possibly happen in the future that could put people with asthma at a higher disadvantage and that could cause them to lose their lives.”

Accordingly, although asthma may be managed through medical treatment, certain external circumstances or unprecedented events (like the COVID-19 pandemic) could heighten the life-threatening nature of the condition.

This was also a crucial consideration when discussing albinism (P4), in which most participants highlighted its potential life-threatening nature due to external factors. Initially, perceptions of albinism varied among the participants. For some participants, albinism was a “unique” and “special” characteristic of a person’s physical appearance, which did not impede his/her abilities (Participant 5). As such, people with albinism may lead normal, fulfilling lives. “[I]t’s not really a very serious thing. Somebody can still live a very good life with albinism, without any problems, so it’s not really a big issue,” said Participant 28.

Conversely, some participants believed that albinism could pose a serious health concern, considering its ability to lead to more severe health conditions, such as cancer. As

Participant 11 remarked: “[P]eople [who] live with albinism have higher chances of getting skin cancer.” In this context, Participant 27 highlighted the increased susceptibility of these individuals to cancer, as influenced by environmental factors:

> “[A]lbinism is a mutation where a person’s cells do not produce any melanin at all […] if that is correct then a person would be at a really, really significant risk of developing cancer, simply because sunlight and radiation would be able to travel straight into their skin and there wouldn’t be melatonin that will reflect it out.”

Accordingly, individuals with albinism may be predisposed to skin cancer, especially with prolonged exposure to excessive sunlight. This is because the melanin deficiency associated with the condition does not provide adequate protection against UV radiation. As Participant 4 added: “[A] person living with albinism cannot live in a high temperature.” This may also result in impaired vision, in which such individuals may experience poor eyesight (Participant 19). In this regard, Participant 22 stated: “[I]t should be allowed, because the risk of skin cancer and, as far as I know, eye issues and general health is definitely affected.” Thus, the participants eventually shared the belief that allowing HHGE for albinism could mitigate the risks of developing other serious health conditions, such as skin cancer or poor eye vision.

Albinism may also be life-threatening due to specific social or cultural factors (Participant 25). To illustrate, the participants raised concerns regarding the connection between albinism and certain traditional African practices, which presented a severe life risk to said individuals.

> “[I]n the Western world, um, albinism is something that were understood. In Africa, or rather, where I come from, because originally, I’m from Zambia, um, albinism has been linked to a lot of things like witchcraft. So, a lot of albinos actually end up being killed.” (Participant 9)

Due to superstitious beliefs prevalent in the African region, individuals with albinism were often killed for their body parts, which were perceived as “the key ingredients for a certain muti” or traditional medicine (Participant 4). Consequently, Participant 25 acknowledged that the condition may be “life threatening because of […] what the society or people are like in society”, or external factors. In this regard, some participants advocated for HHGE applications, considering the life-threatening capacity of albinism, particularly in the African context:

> "[W]ith albinism, in my previous group we discussed if it's life-threatening, as I've made an example where people are being killed for whatever muthi stuff and all those things. That is also life-threatening to the child so I, as the parent, if I can make a decision to spare him or her to not live in fear, maybe one day being killed for that certain muthi, which is a misery […] So if I can spare them that misery, then I can make a decision to edit their genes," said Participant 4.

For Participant 4, gene editing may be utilised to avert the aforementioned life risks associated with living with albinism in South Africa.

However, despite these considerations, majority of the participants supported the conditioned use of HHGE for albinism, where most participants felt that such applications should be left to parental discretion. As Participant 21 provided:

> "The parents are happy with their child, and are not seeking treatment for albinism, then good for the child, but if it's important enough to the parents that they would seek treatment, then I think they should be allowed […]"

*Improves the quality of life*

The participants exhibited great optimism towards the use of HHGE to improve the *quality of life* of prospective individuals, being a primary factor leading to its acceptance. As alluded to earlier, the severity of the health condition was assessed against its potential impact on quality of life. "[V]ery serious diseases can affect a person's quality of life," said Participant 6. For Participant 5, a disease was not only something that was life-threatening but also had a considerable effect on one's quality of life. In her opinion:

> "[A] disease is something that have impact on your life, that will prevent you from doing sport or developing something, or being on your own, or something like that. That is a disease, the potential to change your life."

As such, in declaring their support for the HHGE, the participants either made direct reference to quality of life, or considered the challenges and limitations posed by certain genetic health conditions and their impact on various dimensions of the prospective individual's life. Overall, the well-being of the prospective individual and his/her ability to live a normal and fulfilling life was prioritised. As Participant 5 declared:

> "[T]he most important thing to use the gene editing is to improve the individual's life. The one that is receiving that editing, that individual must be better off […] it must be for his life, you know, to develop a rewarding life."

The participants demonstrated a willingness to explore genetic interventions when the severity of the condition signified a profound impact on the prospective child's physical and psychological well-being (including cognitive abilities). Thus, certain conditions may impair an individual's physical health and mental capacities, affecting the daily functioning of the body.

With serious heritable conditions, Participant 15 indicated the importance of maintaining "a healthy and fit body" in her support for using the technology. Participant 7 also highlighted the interrelation between physical and mental health. Serious conditions like sickle cell anaemia often induce immense pain and suffering, and coping with the physical symptoms may deteriorate mental health, leading to adverse outcomes such as suicide attempts. According to her observation:

> "So, I know for a fact that sickle cell is extremely painful and people that live with it, they're constantly on medicine, they die very young, they often commit suicide. So in that case, I would say definitely. I would say agree with the first statement."

In this respect, HHGE could be used for serious conditions where conventional medical treatments offer minimal relief in alleviating pain and suffering, thereby enhancing the individual's physical and mental health.

Several participants also acknowledged the health complications associated with Down's syndrome (P5), particularly its effect on the individual's cognitive functions. Participant 26 stated:

> "With down syndrome, as other speakers have said, it […] affects almost every other organ in the body, from your brain to almost everything, and it has, we know that it's associated with a […] poor quality of life."

Down's syndrome is caused by "a chromosomal deletion" which impairs a child's "neuro development" (Participant 9). Given this impact, Participant 28 highlighted its ability to affect a child's "intelligence", which was decisive in his approval of gene editing. Thus, some participants examined the severity of Down’s syndrome in relation to its impact on the child’s cognitive functions or intelligence, which could reduce the child’s quality of life.

Participants also supported the use of HHGE for genetic health conditions which could have a significant impact on the prospective individual’s social and financial well-being, acknowledging the challenges that may be experienced in daily living.

When conversing about disabilities, Participant 20 commented: “[L]iving with deafness or blindness, I think it’s one of the hardest things, so if there is any chance of it being prevented, I would definitely do it for my baby.” In this context, Participant 2 elaborated on the limitations presented by disabilities in living a normal life. She discussed how such individuals may find difficulty in accessing employment, seeking a life partner or engaging in ordinary life activities. She stated:

> “I do feel that with disabilities that gene editing will be very beneficial. They can live a fairly normal life but it’s not easy. Finding a job, finding a partner, even doing basic things like shopping, and it does affect your life […] So, I do think that gene editing for a disability like that is definitely going to help a lot.”

Participant 19 expressed a similar concern in relation to Down’s syndrome. She indicated how the condition could hinder an individual’s ability to “be independent […] get married and procreate […]” Consequently, said individuals may be deprived of a family life. Moreover, certain restrictions on their independence may result in dependence on their parents for lifelong support. This point was articulated by Participant 1, who expressed that whilst individuals with less severe cases of Down’s syndrome may achieve a level of independence, others may require substantial, lifelong support from their parents to live a basic life. Thus, she raised concerns about the self-sufficiency of these children after the parents are no longer around to provide support:

> “[I] would also say yes because from a parents’ point of view you would obviously like your child to be able to provide for themselves when you pass away. I’m not saying Down’s syndrome people is not capable, but Down’s syndrome also comes in varying degrees and some people are not, so it’s […] about me saying yes, because of the child being able to look after themselves after the parents pass away.”

Therefore, it was crucial that the health condition did not impede the prospective individual's ability to be independent or sustain a livelihood. In this respect, Participant 25 declared his support towards the use of HHGE for all genetic conditions, precisely if it threatened the "livelihood" of the child.

In addition to this concern, Participant 3 opined that living with Down's syndrome was particularly arduous in the South African context. She highlighted the lack of employment opportunities for such individuals, precisely which accommodate their unique abilities. She emphasised:

> "[W]ith Down's syndrome we still have no jobs for people with such disabilities. You can find one or two people working at Spar but right now there's not a specific, I want someone with a disability of that nature, so, unless we as a society move to improving conditions, then we can look into parents choosing." (Participant 3)

Consequently, these individuals may struggle to find employment in South Africa even if they exhibit a degree of independence.

The participants also asserted that specific health conditions may require ongoing medical treatment or special needs, affecting the financial welfare of prospective individuals and their families. For serious heritable diseases, some participants considered the financial repercussions involved in lifelong medication dependence and highlighted financial challenges. Participant 9 indicated the high costs of treating certain chronic illnesses like diabetes, emphasising that such costs may be financially burdensome even for the "average family". He asserted:

> "[I]n the case of a serious, um, heritable disease, I would go with, um, fully agree. And my reasoning behind that is because, um, the cost of someone dealing with […] heritable disease, even something as, I don't wanna say as simple but, um, related to others, something as simple as diabetes, the cost of treatment is so high that the average family can't afford, um, buying the monthly insulin doses that the child might need."

As such, certain chronic diseases may require continuous medical treatment, becoming a recurring medical expense that may not be affordable to prospective individuals and their families.

With less severe diseases, such as asthma and eczema (P2), whilst some participants felt that these conditions could be managed with treatment, it was still crucial to acknowledge the financial expenditure for both the prospective parent and the individual in accessing treatment. On the subject of asthma, Participant 9 highlighted the expense involved in purchasing "asthma pumps", emphasising that such regular treatments are not within everyone's means.

Moreover, children with disabilities or Down's syndrome require special needs, including access to specialised educational institutions. This could result in increased expenditure for prospective parents. As Participant 9 highlighted:

> "[A] disability like deafness or blindness, I think I would say agree and that's because, um, the cost of […] if we look at the cost of, um, sending your child to a special school for education, um, the costs are actually quite high and not everyone can afford that."

This was also the case with Down's syndrome, where Participant 4 remarked: "[T]here are also special things that must be there for the child. You know how it is, we are not equally financially […]" As such, the participants feared that certain children with disabilities or Down's syndrome may not be able to access education due to financial challenges.

Participant 5 also mentioned that, whilst financial barriers may prevent access to special education, "South Africa is not disability friendly". She highlighted the shortage of special schools in South Africa, declaring that there are only a few available. She provided:

> "Even if you're blind, if your parents can't send you to a special school, that is, how many are there in South Africa? Three or five? There's a long list waiting. If they can't send you, what happens with you?"

Thus, numerous families may not have immediate access to the specialised education that their children require.

### *(ii) Immunisation against serious infectious diseases*

In similarity to genetic health conditions, participants expressed support for the use of HHGE to prevent serious infectious diseases which they perceived as life-threatening or detrimental to the quality of life of the prospective individual, although they were treatable. Furthermore, HHGE could be utilised for immunisation against diseases that were "not always preventable" (Participant 22).

*Life-threatening infectious diseases*

Some participants accentuated the severity of TB, indicating its impact on not only the individual's lungs but other vital organs. As Participant 6 added: "[F]or TB, I fully agree because, it is caused by a bacteria and not only will it affect your lungs, it can affect your kidneys, your spine and your brain as well." Severity was assessed against the ability of the infection to progress into a significant life risk or the potential to become life-threatening. In referring to TB, Participant 10 provided:

> "[I]t comes down to, um, again, what's life-threatening […] A lot of those, uh, diseases, people do die of and it's a very high chance, um, that someone would not survive that. So, for me, I would say, those that are more serious […] that very much have a high mortality rate […]"

Thus, the participant proposes a criterion for evaluating disease severity, advocating that diseases with an increased mortality risk, such as TB, should be prioritised when considering HHGE applications.

In this context, some participants acknowledged the emergence of multidrug-resistant (MDR) and extensively drug-resistant (XDR) TB strains, which present a greater health risk.

> "[F]or TB […] if you can edit it so that you don't get it, that would be very advantageous, and because now we also have multidrug-resistant and extreme drug-resistant, because of non-compliance with antibiotic schedules." (Participant 6)

Thus, whilst several participants advanced that TB could be cured with medical treatment, Participant 6 emphasised its increased severity when antibiotic courses are not completed, leading to the development of particularly severe drug-resistant strains. These TB strains appear more challenging for medical treatment and have resulted in fatalities. As Participant 4 described:

> "I think TB is a very dangerous disease, as it come with, there are types […] of TB which are called MDR and XDR. And some of them, they killed, some people […] have died from TB. So, I think […] the gene editing must be used on tuberculosis."

Consequently, the participants believed that HHGE could be employed to combat TB, given the occurrence of resistance strains which have a higher mortality rate. Reflecting on this stance, Participant 6 added: "That is an issue that we would not face, if it was allowed, to gene edit it, so that we're immune to it."

Although HIV/AIDS was also viewed as a “deadly illness” (Participant 2), Participant 1 indicated that the use of ARV treatment could potentially extend the lifespan of an individual, where she expressed: “So [with] HIV, you can live 20 years, 30 years, 40 years, if you do take the ARV.” However, whilst HIV/AIDS may be managed with medical treatment, it remains life-threatening and a long-term condition. As Participant 1 stated: “[F]or HIV, it is manageable, but it’s still very dangerous. And once you have it, you have it. So, I’d rather do gene editing for […] the illnesses that we don't have a quick cure for yet.” Moreover, gene editing was perceived as a more promising approach towards achieving a potential cure for HIV/AIDS, compared to available treatment methods.

> “HIV has been with us for 40 years, our immune system has not been able to deal with it. Um, even now people are living longer because of medication […] the only thing that is closer to a cure is gene editing.” (Participant 28)

Contrary to TB and HIV/AIDS, most participants believed that the common cold or flu was not sufficiently serious or life-threatening to justify HHGE applications for individuals, and could thus be managed with medical treatment.

> “[I]t’s not something that is a huge thing. Flu, it's something that we can treat, it’s not something that can kill you, or, you know […] if it kills you, it's very rare to find people saying that they got killed by flu.” (Pariticipant 23)

*Treatable but effect on quality of life*

A few participants highlighted particular factors which may influence the individual’s quality of life, such as the prolonged period of medical treatment for TB. Participant 2 asserted: “TB is a very long illness […] And it’s not just one vaccination or, uh, taking one set of antibiotics for a week it’s months that you have to get treatment.”

Participant 26 also indicated the potential high costs associated with treating TB or severe drug-resistant strains. He stated:

> “[T]he people have to use pills or medication, whatever the case may be. So […] those things are costly as well, *you know, so* if […] people misuse, uh, antibiotics and all of that to treat those things as well.”

As such, the availability of treatment does not reduce the effects of the disease on quality of life. “In our group, for gene editing for TB […] we agreed because we thought, even though there is treatment, the quality of life is not the same as not having the virus at all," said participant 24.

In terms of HIV/AIDS, whilst several participants believed that the disease could be treated, most participants considered the impact of the disease on quality of the life. As Participant 24 positioned: "In our group, for gene editing for […] HIV, we agreed because we thought, even though there is treatment, the quality of life is not the same as not having the virus at all."

In this aspect, a few participants advanced concerns about the impact of the virus on the individual's physical well-being, or its ability to impair the immune system (Participant 11). Thus, increasing an individual's susceptibility to other infections. "HIV is […] a very bad, um, factor […] in terms of causing other diseases, such as cancer *or in* how it […] really, it severely reduces one's ability to survive cancer," said Participant 19. Consequently, the presence of HIV/AIDS may also exacerbate the impact of other diseases due to a weakened immune system.

Moreover, even though HIV/AIDS may be treatable, the participants recognised challenges with life-long medication dependence, which may become burdensome. As Participant 6 highlighted: "[E]ven in cases where it may be treatable, but it does decrease your quality of life, because you have to take the meds for the rest of your life once you do have it." Participant 4 also indicated the psychological monotony and fatigue that coexists with the daily consumption of medication:

> "We all know that there are pills that are being taken by people living with the virus […] Those, uh, pills, are suppressing […] the HIV virus […] you have to take them for the rest of your life […] So, I think […] there is a period when someone is tired because sometimes people get tired of taking pills every day, in the same sequence."

The daily pill intake required for HIV/AIDS management presents a lifelong commitment, which may become exhausting and tedious for such individuals.

HIV Individuals may also be subject to societal discrimination, impacting various aspects of their lives, such as access to healthcare and medical support (Participant 17). Some parents may feel embarrassed to disclose the HIV-positive status of their children, obstructing their access to essential medical care. As Participant 17 expressed:

> “[T]here are kids who are born in this way, the parents don't actually care, or they’re embarrassed because HIV is like, um, a virus that people are ashamed of being known that they have. *So*, they hide the fact that they have it, they don't wanna go to the clinic, they don’t wanna take medication, because they ashamed that the people are gonna discriminate against them.”

Thus, if appropriate medical care is not acquired, this would decrease the child’s physical health. Such hesitancy in accessing medical facilities is often linked to concerns about prejudicial treatment or “judgement” (Participant 29) from others in society. This may also prevent access to education or engaging in ordinary childhood activities. As Participant 2 mentioned: “[I]f a child gets it through birth, um, and he, he can’t go to school, he is afraid to play because he knows, he’s got this.” Thus, such children may withdraw from social interactions because they fear being unfairly treated or stigmatised, impacting their overall quality of life.

*“Not always preventable”*

A key factor influencing the participants’ support for using HHGE to provide immunity against HIV/AIDS was the understanding that the disease cannot always be prevented. As Participant 16 asserted: “[I]n terms of HIV […] it is sort of a lifestyle disease, it is preventable, safe practice, and all of that, but there are circumstances that you cannot control.”

Some participants referred to instances where the disease is transmitted due to sexual assault or rape in rural areas. In this respect, Participant 27 stated:

> “[I]f you look at rape survivors, people who have been sexually assaulted and who also contract HIV, or let's say they haven't begun the treatment in time, maybe they were raped in a rural community, far from any access to health care […] They would end up contracting HIV and, it’s these unfortunate circumstances where people don't really have the choice whether they want to be raped or not, but they will contract HIV.”

Thus, the disease may not be preventable due to prevailing societal conditions, where certain rural areas do not have immediate access to health care facilities to prevent the infection after exposure.

Moreover, the disease may be transmitted through birth, where “children who are born to mothers who are HIV positive […] have a risk of […] getting HIV as well.” (Participant 27). Thus, unlike adults who can make informed choices and take preventative measures (in some instances), newborn children do not have control over their exposure to the virus. According to Participant 26:

> "[T]here are other modes that people can *get HIV*, you know […] through vertical transmission […] when the baby is in their mother's womb […] *So there are* other instances where, you know, it's not necessarily that someone engages in unprotected sex or in risky behaviour that they get HIV."

Some people may also get HIV due to "blood transfusion" (Participant 16) or accidental contact with the virus. As Participant 17 indicated:

> "HIV is something that can be prevented, but what happens in the case where you can't really prevent it because it happened without […] you knowing. Like maybe you met up in a car accident and this person next to you is infected, and his or her blood squirts into maybe your eye, or maybe you're all injured and your blood mixes."

Hence, HIV can be transmitted accidently through contact with HIV infected bodily fluids, such as blood. In such circumstances, preventing HIV transmission is not always possible. As Participant 6 stated: "[W]hile it can be termed a preventative disease, in some instances, you can't control it." Thus, participants stressed the importance of using HHGE for diseases like HIV/AIDS, where prevention is not always an option.

### *Sub-theme 1b. Benefits for society*

The participants advocated for HHGE to prevent serious infectious diseases that are prevalent or epidemic in South Africa, posing a "greater threat to society" (Participant 25). "South Africa is one of the ones that has […] a high prevalence of TB and everything," said Participant 16. The participants were cognisant of the profound impact of said diseases on various dimensions of society, including increased mortality rates in the country due to their perceived severity. For example, Participant 20 indicated how TB remains a critical public health challenge due to its severity and high mortality rate. She said: "I believe that TB is very dangerous and then with the stats provided, I've seen that a lot of people have died from TB. So, with that said, I can take the gene editing route." This perspective was reinforced by Participant 4, who acknowledged the significant loss of life during the COVID-19 pandemic, where she stated: "A lot of people died […]." Consequently, as Participant 23 stated, HHGE applications should "prioritise conditions that are very […] severe and those that […] can end up killing people." Thus, improving public health and alleviating substantial suffering. As a result, participants believed that HHGE applications could serve a greater societal benefit by improving public health and overall well-being.

In the context of *serious genetic health conditions*, several participants indicated their support primarily for the positive impact that it would have on public healthcare. As Participant 1 stated: “I totally agree with gene editing for serious health issues […] Obviously, for the effect that it would have on the child and on the healthcare system […]” Participant 16 also shared a similar sentiment, providing:

> “[I]n the context of serious heritable disease, like Alzheimer’s, I think it should be done because not only will you be, you know, helping the person’s quality of life, but eventually, you’re sort of lowering the burden on health, so we can focus on other diseases.”

Despite this acknowledgement, the argument about the overarching societal benefits was more frequent in discussions on *serious infectious diseases*. Accordingly, the participants believed that clinical applications of HHGE for immunity against serious infectious diseases would not only enhance the well-being of prospective individuals but broader society. This was articulated by Participant 6 in her statement:

> “I think it’s important because it’ll [gene editing] also have a beneficial impact on not only the person’s life because they don’t have the risk of contracting that disease, but also it alleviates the public health burden that diseases like […] TB have on our public health services.”

As such, HHGE could be utilised to mitigate the burden of easily transmissible diseases. In this way, it could alleviate the existing strain that said diseases have on public healthcare resources and minimise the economic impact.

#### *(i) Mitigating the burden of easily transmissible diseases*

For the participants, gene editing would be beneficial in reducing the prevalence of infectious diseases such as TB, HIV/AIDS and COVID-19, which are easily transmissible, presenting a significant societal health risk. As Participant 26 asserted: “There’s an opportunity to prevent a serious disease that has […] a health burden on people, and does not affect only the individual, but has potential of affecting more people.”

In this regard, Participant 25 made particular contrast between serious heritable diseases and infectious diseases, highlighting their differences in the manner of transmission and impact on society. He expressed:

> “[M]ore serious diseases, like […] your inherited diseases like […] type one diabetes […] it’s not a communicable disease, right? So you cannot pass it on […] to people you are not related to, you know, it’s […] a genetic disease. It can’t just be passed on to […] everyone in society. So […] on the other end, we have […] your infectious diseases […] these pose a greater risk to society, you know. Diabetes […] can’t just be passed on to random strangers […] in your surroundings. But with your infectious diseases, it can definitely be passed on to everyone in society.”

In his argument, serious heritable diseases, attributable to family genetic factors, cannot be transmitted to the general public. Conversely, infectious diseases have wide-ranging effects, spreading rapidly and widely in society. Thus, impacting societal well-being.

To provide examples, some participants considered the highly contagious nature of TB, which poses a significant threat to not only individual well-being but public health. As Participant 17 stated: “TB is passed on just like any other […] virus. It can be passed on from one person to the next.” In other words, TB is easily transmissible and can affect anyone in society.

In this respect, Participant 18 drew particular emphasis on poor, densely populated communities where multiple individuals often share a single household, increasing the risk of TB transmissions. He elaborated:

> “[I]t will be a good thing that, it could stop spreading TB drastically, as people, especially that live in poor communities where they live together and a lot of people in the house […]”

Participant 25 also highlighted the heightened risk of healthcare workers in a healthcare setting, where he stated:

> “So, with your serious conditions […] like TB […] I definitely think […] they pose a threat to a person’s well-being and not only that person […] they can also spread, you know, so they’re contagious. So, um, your health care workers can acquire such, you know, diseases, um, through nosocomial infections.”

Thus, given the direct and frequent contact with potential carriers of TB, healthcare workers would be at a greater risk of contracting the disease due to their work environment.

When discussing HIV/AIDS, some participants acknowledged that while individual choices may contribute to its transmissibility, it remains "an issue in our society" (Participant 19). Participant 16 also voiced his frustrations regarding the enduring transmission of the virus and an annual increase in infections, despite ongoing awareness campaigns on HIV prevention. He stated:

> "I think if we can, uh, prevent it, you know, because l-l-let's be honest, um, HIV has been around for decades now, and every year we're singing the same song […] but each year we […] still get new cases. So as much as it is preventable, you know, people are still not preventing."

As such, he believes that while preventative measures can be taken (in some instances), they are not effectively implemented by everyone in society, increasing the spread of HIV.

Similarly, when addressing COVID-19, some participants forwarded concerns regarding the futility of the vaccine in averting the spread of the virus, where Participant 6 shared: "[W]ith vaccinations, while they do help decrease the risk of having very severe COVID, we can still get it […] And also, we can pass it on […]" Thus, although vaccinations have been procured, individuals in society may still be vulnerable to infection.

*(ii) Minimising the public healthcare burden and economic impact*

The general consensus was that decreasing the prevalence of serious infectious diseases could lessen their impact on public healthcare resources and the economy. Fundamentally, participants expressed concern about the impact of these diseases on the public healthcare system, given their severity and prevalence in South Africa. According to Participant 22: "TB and HIV […] especially now in South Africa […] are a massive load on the public health care." As such, participants feared that available resources might not suffice in meeting growing demands for medical treatment, hospitalisations and specialised medical infrastructure. To illustrate, several participants emphasised the financial burden borne by the state, precisely when managing drug-resistant TB strains. According to Participant 27:

> "[I]f you look at TB, a lot of patients […] fail to take their medication or they stop taking their medication, and they end up becoming drug resistant. *And* that could cost government more money to treat them […] because their recovery period is longer […]"

As such, the progression of TB into drug-resistant strains may lead to prolonged recovery times, increasing state expenditure due to the need for more expensive treatments. Drug-resistant TB strains do not only elevate treatment costs but also require additional funds to enhance hospital infrastructure, such as establishing and maintaining specialised units for managing new infections. As Participant 16 pointed out:

> "But if we look at […] the numbers, and actually […] the burden on the health system, from just TB. I know there are hospitals that actually j-just have specialised units for TB, because the drug resistant and extra drug resistant, and all of that […] so think looking at it, um epidemiologically, so if we can cut it from the source, then we can free up those specialised units for other things […]"

Thus, genome editing for immunity against TB would allow for the preservation of current resources, shifting the health focus towards emerging diseases that might arise in the future (Participant 16).

Participant 9 also indicated the substantial costs involved in providing ARV treatments, particularly in South Africa, where HIV infections are widespread.

> "If we do look at the […] impact that […] having to provide ARVs to each and every individual with HIV positive has […] on […] the healthcare sector of the country, I think I would have to say I agree […]." (Participant 9)

As a result, participants shared the opinion that the reduction of serious infectious diseases through HHGE could mitigate the substantial strain on public healthcare resources, ultimately reducing state expenditure. As Participant 25 asserted: "[F]or the general good of […] everyone, I think it [gene editing] should be used, you know. Just […] to ease the burden on […] the health system […]"

Some participants also highlighted the potential of serious infectious diseases to disrupt daily life and undermine economic stability. Participant 19 emphasised the impact of increasing TB cases on workplace productivity. She added:

> "[W]ith TB, there's horrible side effects that come with that. So if you think of just the work force, the South African work force, any country's work force, actually, if you think of how much down time there is due to them taking treatment." (Participant 19)

As such, employees who are affected by TB would require time off to recover, resulting in decreased productivity and efficiency in the working industry.

This was a core argument when discussing COVID-19, where some participants indicated their support for HHGE applications due to their first-hand experience with the effects that it had on society, including an economic downturn (Participant 20). As Participant 6 remarked: “For COVID-19, I also fully agree, because as we’ve seen, it has had catastrophic results and effects on society and life as we know it […]” This included disruptions in the working industry, where Participant 1 highlighted the increased strain on governmental resources in providing financial relief or an “SRD grant” to individuals who lost their jobs. She provided: “[T]hey also had to pay more money out for people that lost the income. So, the SRD grant, all those things, […] cost a lot of money.”

Thus, most participants supported HHGE applications to prevent infectious diseases which pose a direct threat not only to individuals but also to society.

> “I think that if there’s any way to kind of decrease serious diseases […] that will inconvenience us, whether that’s personally, or like COVID has done with our whole entire life, I think it should be done.” (Participant 6)

### *Theme 2: Future implications for natural immune responses*

Theme 2 addressed the participants’ concern with respect to the future risks of HHGE applications, precisely when editing to impart resistance against less severe infectious diseases. While the participants acknowledged the potential therapeutic benefits offered by HHGE, they feared that applications for less severe diseases were excessive and could inadvertently produce negative outcomes for prospective individuals, including the potential loss of natural immunity.

### *Subtheme 2a. The potential loss of natural immunity*

Genetic modification for immune resistance could have adverse effects on natural immunity. This concern was widely shared among participants, especially when discussing less severe infectious diseases like the flu or common cold. Participant 27 elucidated: “[A]s much as it would be great to have kids immune to simple viruses and common colds like the flu, I would worry about the natural immunity that develops in […] children as they grow up.” HHGE applications for immunity against less severe illnesses were considered excessive or what

Participant 28 described as “an overkill”, considering its potential to lead to more significant health outcomes such as the loss of natural immunity.

Human beings possess the natural ability to develop immune responses to infectious diseases, usually acquired through pre-exposure to pathogens and vaccinations. As Participant 2 explained:

> “[T]he vaccination for the flu is so good now that […] our bodies naturally made immunity against it […] natural genetics have made that some people don’t really get flu or the common cold, and that is a natural thing that started happening. And the same thing will happen with more of the viruses that we do contract, to just give us, our bodies, chance to naturally […] deal with the viruses that we do encounter.”

Thus, acknowledging this inherent capacity, most participants favoured the natural development of the immune system over genetic modifications.

Furthermore, most participants argued that allowing the body to come into contact with these minor diseases was integral for the development of natural immunity. This point was articulated by Participant 10, where he added:

> “I think it comes down to […] building up the immune system […] of a child. And that as well, […] we’ve seen with […] other viruses and other […] illnesses that […] having exposure or having been sick with a different type of virus that is similar, will give […] your immune system a better chance of fighting off that virus, even if it’s not exactly the same virus again. I’m more likely to be a […] normal, healthy human being if you have been exposed to other viruses in your childhood.”

In his opinion, exposure to different viruses or pathogens during one’s growing years was crucial for strengthening or boosting the immune system. As such, the body would be better equipped to combat future infections, even if these viruses have not been previously encountered.

Some participants also noted the significance of viruses in other evolutionary processes which were pivotal to human development. To illustrate, Participant 22 indicated how the human placenta had evolved from interactions with a virus. He stated:

> “[H]umans, as far as I know, never used to have placentas in the womb, which filter a lot of […] toxins […] it’s thought many thousand years ago, um, a virus actually mu-mutated us to

> have a placenta. It was a completely unintended thing, um, of course, but […] it's quite advantageous."

Participant 14 also asserted that viruses had significantly contributed to technological advancements, such as the development of the CRISPR-Cas9 technology itself. He opined:

> "[T]he bacteria that we owe much honour, um, for this technology, I think it has evolved over time, um, precisely because […] viruses have been part of […] their system […] for quite a long time, and they've kept that […] within their genome. So I would assume that, in a sense, there's been an […] interaction between the virus and the bacteria for quite a long period of time […] and without such an interaction […] I'm imagining […] whether we would have had a chance to interact with such a technology."

Therefore, despite negative perceptions of viruses or pathogens, certain interactions may result in unforeseen advances that ultimately benefit individuals. In this context, the participants argued that it was important to preserve such evolutionary interactions, including the exposure of prospective individuals to viruses or minor illnesses which were a part of natural processes. Accordingly, Participant 14 stated that using HHGE to confer immunity was "speeding up evolution", potentially resulting in unintended consequences for the prospective child.

Consequently, using HHGE for immunity could circumvent natural pre-exposure to certain viruses or pathogens crucial for natural immunity. Thus, Participant 9 feared that gene editing applications, in this respect, could hinder the "body's ability to […] build up its own defenses." Some participants also expressed this view when discussing COVID-19, where Participant 25 added:

> "And then with your COVID-19, as well as the flu and common cold, I definitely think it should not be used […] for the simple reason that […] it might affect or compromise your immune system."

Thus, concerns were raised regarding the long-term effectiveness of genetically engineered immunity. Would genetically engineered immunity impede the growth of natural immunity? If so, would it make the prospective individual "more vulnerable" or prone to future infections (Participant 10)? Alternatively, would it be as effective as natural immunity in fighting off these diseases? These were the questions raised by most participants when discussing the future implications of using HHGE for immunity.

> "[W]hat are the long-term implications […] and how would someone's immune system cope in the long run? How would they develop? How would they grow? Would they be the same as someone who isn't gene edited and can't fend off these normal, simple viruses?" (Participant 27)

*Theme 3: Equitable access to HHGE for everyone*

Theme 3 addressed a principal concern that HHGE would not be equally accessible to everyone once it becomes available to the general public. This could heighten current socio-economic inequalities. As such, the participants raised questions regarding the affordability of HHGE and potential financial barriers that may prevent certain socio-economic groups from accessing the technology. They emphasised the need for public sector intervention in this regard, to ensure equitable access of the technology to everyone, whilst acknowledging the challenges that the government may encounter in achieving said access.

*Sub-theme 3a. Financial barriers and active government intervention*

The participants advanced concerns about the affordability of gene editing and the exclusion of certain socio-economic groups due to financial barriers. Participant 14 feared that if HHGE is made available, it could be restricted to specialised fertility clinics which are not affordable to everyone. He added:

> "I agree but with certain conditions […] my issues were around inequality […] if this was in fertility clinics, it could somehow exclude other sectors of the society […] So, accessibility is quite important […]"

Most participants feared that low-income persons lacking the necessary financial resources may be unable to access gene editing treatments. Participant 4 made direct reference to impoverished individuals "living on a minimal wage", who may be marginalised. Elaborating on this position, Participant 1 added: "[I]f you have more money you can treat it or if you are richer then you will be able to access the gene editing […] and the poorer person will not be able to access it […]" Consequently, participants expressed concerns that gene therapy may primarily benefit high-income individuals who would be able to access the technology, leaving other societal groups to cope with disease. In this regard, Participant 10 posed the following question: "[D]oes it become such that it's so affordable, uh, it's available to everyone […] or is it something that, you know, only the rich can afford and everyone else is subject to living with it?"

As such, the participants had reservations about the use of HHGE, precisely if it could create a scenario in which poorer individuals are unable to access the technology and are subsequently disadvantaged. They expressed fear that this disparity could reinforce existing socio-economic inequalities present in society, if the government does not effectively intervene. According to Participant 14:

> "[T]he government should play a huge role in […] being part of this new change and making this quite accessible to everyone in order to, not to divide the gap further to increase the inequalities within our societies as it is already quite an inequitable society."

Thus, the participants agreed that HHGE should be made accessible to everyone through active government intervention. This discussion was prevalent when addressing genetic health conditions. In some discussions, HHGE was equated to conventional medical treatment or "medicine", suggesting "that it should affordable" and accessible to everyone (Participant 16).

Whilst the participants shared this sentiment, most agreed that accessibility should not be a pre-condition to allowing HHGE applications. This was a matter that needed to be addressed promptly, alongside the implementation of the technology. As Participant 26 emphasised:

> "[A]nd whether […] it should be a precondition or not for allowing the use of gene editing and I think we agreed that it should be a concurrent discussion that happens because, you know, we'd be editing genes and all of that for the benefit […] it should be a discussion that happens concurrently."

Aside from the argument that the potential benefits of gene editing should not be delayed, participants contended that if accessibility is not made a pre-condition, the technology could become more cost-effective due to increased demand, becoming widely accessible over time. This was articulated by Participant 22 in his analogy:

> “[I]t should be allowed for individuals before the government can afford it. Because in that way, it often gets more reliable and cheaper […] So everyone wanted a cellphone, and initially no one could afford it, so just the rich people or just those who could afford it got it, and because there was a demand for it, as we know there will be with gene editing, it got cheaper and more accessible and now nearly, most people have cellphones.”

Thus, similar to other technological advancements, an increased demand for HHGE in the future could make the technology more accessible.

However, Participant 26 stressed that the issue of accessibility should still be actively addressed by the government, indicating the need to initiate said discussions early. He feared HHGE could “take a long time” to become accessible to everyone (Participant 26).

Thus, the participants found common ground in their belief that HHGE should be made accessible to everyone through vigorous government intervention. For one participant, the government’s response to emerging technologies (such as HHGE) shouldn’t be restricted to regulating access. He urged for proactive measures in fostering technological innovations in South Africa, such as financing research and incentivising intellectual property growth in the country. As such, he emphasised:

> “[T]he policy should be more pronounced and it should incentivise such innovators […] I’m not expecting the government to simply to be a passive actor whereby the private sector develops new technologies and it just comes on board and it simply regulates the sweat off of the private sector. I would expect it to be a part of this, to fund programmes such as this […] So, to have a reactionary legislature that simply seeks to impose legislation that provides for access to this technology, for me it’s a bit lazy, for a lack of a better word.”

Thus, the government should assume a leadership role in advancements such as HHGE, beyond merely regulating access to the technology.

The participants proposed two strategies in which the government could ensure equitable access to HHGE for everyone. In the first one, the participants advanced that the government should provide equitable access to HHGE for serious health conditions first, before subsidising treatment for less serious conditions. According to Participant 26:

> "[G]overnment should then subsidise people to access that service, but also, you know, with a focus initially on more serious conditions and then later on with conditions that there is currently medical treatment for, you know."

The participants took this decision because they feared that more severe health issues may be neglected if less serious conditions are given precedence. As such, they suggested that gene editing should only become available for less serious conditions, such as asthma or eczema, once treatments for serious genetic conditions have become equally accessible to all. As Participant 3 provided:

> "[T]he reason for me not agreeing fully is because if less serious illnesses are given, what is it, the room to be fixed first, it means there are some more serious issues that can take a backseat so I'd rather focus on the more serious issues, first."

The participants also acknowledged potential government budget constraints, where the government may only be able to fund serious health conditions. Participant 22 provided:

> "The one thing I would add is just that initially, because of affordability and cost and difficulty and all of that, the government might have to initially only focus on the more serious ones, so let's say blindness or the sickle cell anaemia, those sort of things, and then later start moving onto asthma, but I think that they should work to cover all of them."

Thus, accessibility to gene editing should be reserved for serious health conditions, precisely when state resources are scarce. However, the government should still make gradual attempts to cover all genetic health conditions over time.

With respect to how the government ought to assess disease severity and regulate access, Participant 27 highlighted the importance of establishing clear scientific criteria for eligibility, suggesting that access to HHGE should be restricted to future individuals with medically diagnosed, severe conditions.

> "I would say that the government should make it accessible, but they should impose certain restrictions or certain criteria when it comes to gene editing. Like… the person who needs it, they should be diagnosed with something that is a real medical illness, something that has a diagnosis that […] has been diagnosed by a doctor, something that is, um, that has a scientific basis. And I think that the government should use this criteria to make sure that the right […] patients get access to gene editing, instead of everyone getting access to gene editing […]"

In his opinion, this approach could prevent the misuse of the technology for trivial or minor health conditions, ensuring that serious health conditions are prioritised.

Additionally, Participant 29 recommended that the government undertake research similar to this study to gather national perspectives on serious and less serious health conditions, aiding in the definition of serious health conditions and the allocation of state resources. He opined:

> "I think that the government definitely has to come up with […] a list of what's serious and what's not serious, and focus the budget on the serious diseases […] I think they should and how […] they should decide, I think, is through something like this, through this type of research, to try and get a feel of the whole nation and what they consider serious and not serious diseases."

The participants' second strategy included a targeted approach, in which low-income societal groups are prioritised. In this respect, the participants asserted that the government should subsidise said individuals, whilst particularly affluent societal groups should not be eligible for financial support. As Participant 23 asserted:

> "[T]hey should start with those who really need it, you know, if they cannot afford it, let government cover the costs, but to those who are able to have it, like those people who have medical aid, or those people who have money, they can also do it, but medically for those people who are really in need of it first."

As such, most participants deemed it more pragmatic for the government to intervene in cases where financial barriers might impede access to gene editing. Accordingly, the government should provide financial support only to those who would not be able to afford gene therapy, ensuring equitable access for all. "[T]he ones that are underprivileged and cannot afford to pay for it, that's where the government should fund them," said Participant 15.

For the participants, financial capability should be a substantial factor in determining whether HHGE should be made accessible at individual level. In this context, Participant 4 proposed that each individual meet specific qualifications prior to receiving government subsidies or financial support. She indicated:

> "[T]hey must look at your profile, where do you live, what kind of job do you do, will you be able to do this on your own? If you are, then I think the person should do gene editing on their own, if they can afford. But if a person cannot afford, it must be accessible."

As such, financial capability should be examined against an eligibility criteria, where relevant socio-economic factors are considered when determining the provision of access.

*Subtheme 3b. Governmental challenges in ensuring equitable access*

Although many participants supported the notion HHGE should be made accessible by governmental intervention, some voiced doubts regarding the government's efficiency or capacity to make the technology accessible to everyone. Participant 4 articulated this sentiment, stating: "[B]ut you know our government, how it is, what is happening […] some people will not have access to gene editing."

Participant 10 highlighted the particular socio-economic challenges in South Africa and its current shortcomings in delivering essential services. He provided:

> "I think in South Africa, it represents a very unique challenge, right? We have overall a very low standard of living in South Africa […] we're in a, in a country where the government is struggling to make even basic services work, never mind, you know, something as advanced as gene editing […]"

As such, implementing advanced technologies, such as genome editing, would pose a significant challenge in South Africa due to the present infrastructure. Participant 25 particularly highlighted the existing strain on the public healthcare sector, noting that the majority of South Africans depend on public healthcare services. This reliance creates a high demand for medical treatments that cannot be met due to the limited availability of resources. He emphasised:

> "The government will fund […] the technology, the use of the technology, um, but I think it won't be accessible to everyone in society. Because, um, with the public sector, most people […] in South Africa are using the public sector, so, um, there'll be a huge backlog in, you know, […] the use of […] such technologies."

Consequently, some participants believed that prioritising access to genome editing for individuals with serious health conditions and low-income backgrounds would require collaborative efforts between public and private healthcare. In particular, Participant 22 opined:

> "[T]he government and the private sector should work hand in hand and definitely for those who can't afford it, especially for serious issues, should have it covered for them."

Participant 23 indicated that relying solely on government for accessibility could result in long waiting periods and delayed services. Thus, the private sector should intervene to alleviate this potential shortcoming. She stated:

> "[I]f we all going to depend onto the government, and we know the long queues when it comes to the government provided things […] because if you're only gonna depend onto the government, then gonna wait for close to five years on the queue, so, let there be a backup of […] private sectors stepping in to help people […]"

Moreover, the government may lack the technical expertise and resources to make HHGE accessible to everyone, requiring the assistance of the private sector in this respect. As Participant 26 stated:

> "[O]ne of the things is that government may not have the technical know-how and the facilities to actually […] make those things available to the communities or to the people who need them. So, they would be needing the private sector, so then they should be in engagement […]"

### *Theme 4: HHGE and discrimination in society*

Theme 4 explored how HHGE applications could potentially influence discrimination in society. There is a concern that genome editing applications to prevent genetic disorders or diseases could aggravate societal prejudices and discrimination towards individuals living with those conditions. This could negatively impact the societal acceptance of such individuals. Whilst this was an important consideration, the participants expressed that the objective to promote societal well-being best aligned with the purpose of the HHGE instead of reinforcing discriminatory ideals.

#### *Subtheme 4a. Negative impact on societal acceptance*

Several participants believed that HHGE applications for disabilities or other conditions could exacerbate current societal attitudes and promote discrimination towards said conditions and individuals living with them. In this way, it could reduce societal acceptance of individuals who deviate from societal norms. Participant 25 effectively conveyed this point, expressing:

> "So, in my group I had raised that with things like disabilities as well as albinism, the gene editing should not be used, and the reason is simply that I feel like, you know, it could have a negative impact on society's ability to be more accepting to so many conditions and to people who are not perceived as normal in society […]"

He further suggested that avoiding gene editing applications for such conditions could better improve societal acceptance. He opined:

> “[I]f we don’t allow gene editing for people with alb-albinism, think it will […] allow society to be more accepting, right, to people with albinism and other […] non-conventional things in society […] I think it will create a society which is more accepting of people who are not conventional, people who have albinism […] people who are living with disabilities, people who are deaf, people who are […] paraplegic […]”

As such, disallowing parents to prevent disabilities or albinism using HHGE could have an overall positive impact on society, enhancing societal acceptance and creating an inclusive environment for individuals living with these conditions.

*Subtheme 4b. The objective to improve societal well-being*

Most participants asserted that, even though gene editing applications could reduce societal acceptance of individuals living with disabling conditions, the core purpose of gene editing was not to promote or perpetuate discriminatory ideals. Instead, it was perceived as a technological advancement that could better serve humanity, preventing health conditions that seriously affect human life. According to Participant 10:

> “[T]here was a consensus there that, you know, we’re not necessarily discriminating against people who have those diseases, we’re making advances with technology to improve the life of all humans […] Rather than to be born with a disease that was entirely preventable.”

Participant 26 also noted that whilst the impact on societal acceptance was a valid concern, it should not detract from the broader purpose of HHGE, which was to improve the quality of life of individuals. He stated:

> “[T]he discussion of the social implications of genetic editing should not be conflated with you know, as much as it is an important aspect […] we should not miss the point of why we would be doing genetic editing in the first place […] So […] we are going forward with genetic editing, and these are the reasons why – want to improve the quality of life for people, want to, in terms of costs and all of that and how people are subjectively affected by disease […]”

Thus, gene editing was not devised to uphold discrimination but to improve the quality of life and alleviate the hardships experienced by individuals with disabling health conditions.

Some participants argued that even if society accepts people with such conditions, the quality of a disabled child's life is still incomparable to that of an abled child. As Participant 11 stated:

> "[W]e can accept them, we have accepted them, but then, we must remember that their lives are not as easy as ours, because they spend more, they always have to go to the doctor, they have to buy assistive devices and they have to go to special schools, so this all makes their lives a little bit more difficult. So, it'll be easier if they are a bit, let me not say normal, but then, their lives will be easier."

As such, permitting gene editing applications in this regard was about recognising the challenges that these individuals undergo in their daily lives and using gene editing as a means to eliminate said challenges, thereby improving quality of life.

For Participant 19, it was a matter of "empathy", acknowledging that such individuals were in an unfavourable position compared to others. Moreover, HHGE presents an opportunity to correct this disparity for future generations. She added:

> "You would be realising that they're at a disadvantage, and you wouldn't want to put yourself in that disadvantage […] It's realising that people with diseases and disabilities suffer and have life a little bit more difficult than an average person, and trying to prevent that from happening to our own children or the next generation. So, it's not a matter of acceptance, it's a matter of preventing injustice and inequality, given that we have the opportunity to. It's empathy. It's realising that people with diseases and disabilities suffer and have life a little bit more difficult than an average person, and trying to prevent that from happening to our own children or the next generation […]" (Participant 19)

Participant 21 also emphasised that it would be unjust for prospective children to be denied medical treatment on the basis that it would promote discrimination or influence societal biases.

> "I don't think it should be on the child's shoulders to have to deal with people's societal attitudes. I think that's an unfair thing, that's a problem with society, it shouldn't be the child's problem. So, yes, I mean it's all very well saying we shouldn't change a child or treat a child to not have albinism, because then we would just be encouraging society, but I don't think it's fair on the child that society has these issues, rather don't put it on their shoulders […]"

Thus, the prospective child should not have to carry the weight of addressing societal issues, which is a matter that needs to be addressed separately.

Moreover, Participant 6 noted that despite current educational initiatives to promote societal acceptance of individuals with disabilities, said acceptance still remains a problem. This concern is supplemented by her personal experience, which was expressed as follows:

> “[A]cceptability for disabilities. It’s already a problem in society and I think that even with education initiatives that have been happening, it’s still not something that we have fixed, and as someone that lives with a hearing disability, it’s not something people readily accept.”

Drawing from this experience, Participant 6 asserted that HHGE applications should still be permitted as these were social issues that would persist.

> “[I]ts up to the parents to decide, like, what you're going to do because people are going to be unaccepting no matter what happens in society, so I do think it should be allowed even if acceptability does go down.” (Participant 6)

Moreover, Participant 22 highlighted that, at present, it is unlikely that HHGE would be met with robust public objection:

> “I think it depends on the social issues it would cause because, for example, in this study, in the previous part before the breakout groups, I didn’t see anyone who was objecting strongly to any of the points, so […] it doesn't at this level at least seem that there would be large-scale protests, not like physical marching protests, but protests against gene editing.”

He elucidated that if such objections occur, educating society on the advantages and disadvantages of HHGE and further incorporating public opinion may prove beneficial in developing a knowledge base on which a revaluation of the appropriateness of the various aspects of HHGE can be done.

### *Theme 5: The right to autonomy*

Theme 5 examined the potential of HHGE applications to limit the autonomy of prospective individuals, particularly when applied to genetic enhancements. The participants feared that such interventions may curtail individual choice and the child’s future right to exercise free will. While parents are instrumental in guiding the development of their children, questions were raised about the boundaries of parental authority. Thus, it was important that the exercise of parental authority did not inadvertently undermine the child’s future autonomy. The capacity to make individual choices and express free will was considered essential for self-discovery and acquiring a personal identity. In recognising the significance of self-discovery, participants accentuated that parents should avoid using genome editing as a tool to potentially project their interests on their children. The participants raised additional concerns about the inability of prospective children to provide informed consent, precisely to matters which affected their personal autonomy, and had enduring consequences that they would eventually have to suffer.

*Subtheme 5a. The preservation of free will and personal identity*

The participants acknowledged the significance of the inherent capacity of individuals to make independent life decisions and to exercise free will without external intervention. According to Participant 27:

> "[T]he basic condition of being a human being is having autonomy, being able to choose for yourself what is right and wrong. Being able to choose your own destiny, and to choose your own fate, your own beliefs."

In his opinion, the core aspect of the human experience lies in the right to autonomy, which includes the freedom to act in accordance with one's moral values and to determine one's own life path. In this context, many participants contended that this right may be compromised if parents are permitted to predetermine the characteristics of their children, inadvertently influencing their future life decisions.

To illustrate, Participant 19 stated that allowing parents to select certain talents for their children, such as intelligence, may already be directing them towards a particular life path.

> "So, now, if we had somebody that was born with like a predisposition of being more intelligent than others, that also affects, um, somebody's free will. Ok. If somebody would have been creative and naturally went along with their creativity, to have them born, um, with, you know, an aptitude for the hard sciences […] we have made a choice for the child." (Participant 19)

As such, although the parent would not directly determine the life path of the prospective child, enhancing their intelligence through HHGE may be automatically "steering them towards something" (Participant 19). Thus, advancing them towards a career path that they may not have chosen with their naturally acquired talents (Participant 19). Essentially, the child's ability to exercise free will or individual choice is constrained before they are even born. Participant 4 highlighted this by stating: "[Y]ou really do not have the free will because you don't have a choice. You are still on your mother's womb, you are still there. It is decided for you."

Similarly, when discussing sexual orientation, most participants believed that this decision should be preserved for the prospective child, enabling the exercise of inherent free will.

> "I believe it's a choice, what you do in terms of your sexual orientation […] ultimately what you do, and what you become attracted to in, later in life […] that should be up to you as a person." (Participant 26)

Participant 8 also stated: "I don't think we should […] interfere with the person's sexual, uh, orientation, because by doing that […] we are violating their human rights and free will." Consequently, the participants asserted that the expression of one's sexuality should be a matter of individual choice or personal autonomy. If individuals are denied this freedom through genetic intervention, it may undermine their free will, as their parents would have already made this choice for them prior to birth. As Participant 4 expressed:

> "I think that is my concern, because if the parent has decided already before the child is born, the child can no longer do *anything*, or there is nothing that he […] or she can change, because the parent had decided for the child."

Conversely, although parents often play an active role in guiding the development of their children, Participant 19 felt that this was an "invasion of […] your free will to a much lesser extent, than when they can nit-pick your eye colour." Participant 24 shared a similar view, indicating:

> "[A]t a certain age […] the parent is then liable to make decisions for the child, for what's best for the child. But then […] me changing the personality of my child, am I not violating my child's rights?"

In this regard, the participants raised concerns regarding the boundaries of parental authority or influence. They emphasised the importance of safeguarding the child's prospective right to autonomy, ensuring that parents do not unduly infringe on this right through gene editing applications. For Participant 1, permitting parents to decide the sexual orientation of their children was “overstepping” moral limits. Thus, she posed the question: “[W]ho gives us the right as a parent to choose, uh, the sexuality of a child?”

The use of HHGE for enhancements was deemed an extreme measure in exerting parental control, owing to the irreversibility of the induced changes. As Participant 22 asserted:

> “I think it’s […] going to choose too much […] for your child. You’re kind of trying to decide their future ahead of time, um, in a way that they can never change, and […] I don’t agree with that.”

Moreover, such applications were considered unnecessary, lacking therapeutic motivation. As Participant 19 stated: “It’s something that is not […] a critical issue, or a health issue. It’s not something that causes suffering.” Accordingly, when discussing HHGE for disease prevention, most participants agreed that the potential therapeutic benefits warranted parental choice, limiting the future autonomy of the prospective child (for a greater benefit). Participant 26 expressed a strong view in this matter, stating:

> “[M]y views on that would be that parents decide for children from the moment they are born until 18, in some cultures, 21 in some cultures and you know, so basically deciding for the child is what parents do, so […] if a parent can decide as participant 4 was saying, that it would be, I can spare a child misery and all of that, then definitely you should be doing that.”

Parents would usually act in the best interests of their children, which includes the utilisation of HHGE to confer a medical advantage. In this context, Participant 4 remarked: “[W]ith this gene editing, you’ll be selecting, yes for your child, but parents in most cases, you always know what’s best for your child.”

On the other hand, participants agreed that non-medical or cosmetic changes should be preserved for individual choice, enabling prospective children to make these choices independently as they mature.

> “[W]hen you are older, you could always choose to do these things, because as we all agree, it’s cosmetic […] So you could always choose if you want a gender […] reassignment, if you want plastic surgery, if you want a skin darkening or skin lightening, you could always do that.” (Participant 19)

Thus, it was crucial that prospective children be granted the opportunity to make these decisions independently later in life.

The participants argued that the capacity to exercise free will and make independent decisions was important in shaping one's personal identity. As Participant 18 stated:

> "So, with the whole identity thing […] the reason I think everyone is more concerned about, um, identities, because […] for you to […] get that identity of who you are […] it's your own free will of you growing up and choosing what you like and what you don't like."

As such, the process of self-discovery encompasses the ability to make personal choices, explore individual preferences and ultimately develop a natural identity.

For Participant 23, it was important for prospective parents to allow their future children to seek their own ambitions and pursue their individual life passions. Participant 11 expressed a similar sentiment, stating: "Why not give them the choice to […] actually discover themselves and live their own lives?" Consequently, if parents predetermine certain characteristics or traits for their prospective children, it could hinder the child's freedom to establish his/her true identity.

Additionally, the notion of dictating a child's characteristics or abilities was likened to "programming" children to align with parental expectations (Participant 23). As Participant 29 stated:

> "I mean, programming is […] what we're doing. That's what we going to end up be doing if we're allowed to do this. We're going […] to program how we want our child to be, how we want our child to look, what they're capable of."

Thus, the participants expressed concerns that parents may genetically enhance their children for personal gain. According to Participant 2:

> "[T]hat is taking away freedom of choice for your child, uh, it's like you are controlling his life to benefit yourself. Um, you get these parents that push their children to be athletic, because it's a type of, um, they want to look like these suburban parents that, their kid is good in sports or very intelligent, and they themselves benefit from it, but never asking the child, actually, if that is what they want. […]"

The Participant fears that if gene editing applications are permitted for talents such as intelligence or athleticism, some parents may prioritise their own desires or societal expectations over the potential interests of their children. In this way, parents may attempt to enhance their self-image, however, at the expense of the child's future autonomy.

Participant 9 suggested that parents should instead encourage their children to develop their own identities, advocating for individual choice.

> "Children grow up to make those choices for themselves. So I think in this case, we can still leave that up to choice. So as the child grows, they'll learn to know what they like, and what they don't like, what they want to be."

The participants raised an additional concern regarding the potential "alienation" of prospective children when parents select traits or physical features that are not similar to their own (Participant 21). This could sever the genetic connection between parents and their children, which is significant for personal identity. This point was elucidated by Participant 14, who added:

> "I think [...] when someone said, um, I got it from my mama, you know, I'm imagining a young person born in 2122, um, would she take pride [...] in that statement, to say, I got it from my mama, you know? And...will there be any connection between this particular child...and her mother, you know? Um, what does it mean for her identity? What does it mean for the lineage? [...] let's say, this particular trait, um, she took it from her grandfather, she took it from his grandfather, now, we are denying this child, um, that satisfaction and that history [...]"

As such, Participant 14 is concerned that altering genetic traits or characteristics passed down through generations may sever the biological link between prospective children and their progenitors, potentially depriving them of their ancestral history or true identity. This genetic connection did not only confer a sense of pride but was fundamental in understanding one's family lineage or heritage.

### *Subtheme 5b. Informed consent and future consequences*

The incapacity of prospective individuals to provide informed consent to a procedure which could affect their future autonomy prompted concern for most participants, precisely regarding the future repercussions.

Participant 27 argued that prospective parents should not use gene editing to enforce their will on their children or make decisions for a life that they would not personally experience. Thus, it was crucial to respect the autonomy of the prospective child, which involved the ability to make these decisions independently. As Participant 27 stated: "Being a human and being autonomous means that we can only make our own choices, not the choices of someone else."

Consequently, some participants feared that the prospective child may disapprove of the genetically induced changes, given that the parent has taken this decision on his/her behalf. Participant 25 questioned: "[B]ut what does the child want, you know? Um, yes, you've done these changes, but later on in life, will the child be impressed with such changes?" In this respect, the participants were uncertain as to whether the prospective child would declare happiness or rejection towards said changes. This uncertainty was significant as the participants acknowledged the irreversibility of said changes.

> "I think that is my concern, because if the parent has decided already before the child is born, the child can no longer do *anything*, or there is nothing that he or […] she can change, because the parent had decided for the child. So that is my opinion. I think […] when you say it's consent, I think it's consent." (Participant 4)

As such, Participant 4 expressed concern that if parents are allowed to genetically modify their children, the child would be unable to reverse these changes later in life. She emphasised the importance allowing the child to provide consent, precisely for a procedure that would result in irreversible changes.

Similarly, some participants highlighted that the genetically induced changes may not correspond with the child's future interests or individual preferences. As Participant 9 opined, these are "physical characteristics, personality traits, which you are not sure that […] the person, um, in future, would have wanted." Participant 19 indicated that the prospective child may have favoured a different genetic modification or their naturally acquired appearance over the one selected by his/her parents.

> "[I]t's entirely a different argument when your mom has chosen […] a light skin complexion for you, and you would have preferred to have […] a darker one. Your mom has chosen for you to be tall, and you would have preferred to be short. You would have preferred that your mom just let things happen as they may." (Participant 19).

Thus, the issue of whether the genetic changes would reflect the child's future interests or preferences was a fundamental uncertainty that could not be predicted or risked at this point.

Several participants also indicated instances where parental decisions regarding genetic enhancements could have grave consequences for the prospective child due to contextual factors. For example, if the parent has selected a sexual orientation which is not accepted in a particular country, or where it is considered a capital crime. Participant 22 pointed this out when discussing homosexuality, noting how such individuals are potentially killed due to religious or cultural beliefs in certain regions. He stated:

> "[L]et's say your parents decide to make you gay, and that's very […] unacceptable in many cultures and many religions, uh, many countries too […] and in some countries, you can be killed for it, and *completely* legally. And to actually be killed for something that your parents chose […]"

Therefore, it is vital for prospective children to provide informed consent or to make these decisions independently, being fully aware of the potential repercussions. However, if this choice is made for them, they would now have to bear the consequences despite not having made this decision independently.

### *Theme 6: Going against human nature*

The manipulation of human genetic material to enhance traits or physical attributes was considered an interference with natural processes, defying human nature itself. This practice could produce long-term ramifications for both prospective individuals and society. Theme 4 illuminates several moral arguments raised by participants on this matter. For the participants, HHGE applications could initiate a slippery slope towards the creation of designer babies. This provoked thought about the potential ethical dilemmas, including, where to draw the line for permissible genome editing applications and the risk of commodifying human life. Furthermore, intervening in natural processes could have far-reaching consequences for society, such as disturbing the balance between nature and nurture, and reducing genetic diversity essential for the functioning of society.

*Subtheme 6a. Heading down a slippery slope*

*(i) The creation of designer babies*

Genomic modification for enhanced traits or aesthetic characteristics, if permitted, could initiate a "slippery slope", leading to the creation of designer babies (Participant 6). As Participant 24 elaborated:

> "[W]e might start with intelligence and then we move on to, now, your skin colour, now everything, you, you'll be able to change everything about your baby. So, meaning that you'll be designing your own baby. That's where the whole designer baby comes in." (Participant 24)

Thus, initial gene editing applications to improve talents could progress to more unethical modifications, such as altering aesthetic characteristics, potentially allowing prospective parents to design or customise their children.

*Where do you draw the line?*

Participants feared that if HHGE for genetic enhancements were authorised, it would be difficult to establish the line for ethically permissible modifications, precisely when the technology is utilised for non-therapeutic purposes.

Whilst acknowledging the value of genome editing in combating diseases and improving health, Participant 21 expressed discomfort around its usage for genetic enhancements or the notion of handpicking the characteristics of prospective children.

> "I'm sort of unsettled by the whole idea of, uh, designer babies. Now I understand in terms of, um, when you prevent diseases, and […] help the general health and well-being, but in terms of enhancements, or just in general, pick and mix the characteristics of the child, that sounds […] quite […] unethical." (Participant 21)

It was also interesting to note, while genetic enhancements were disapproved by a significant majority, several participants favoured its use to increase intelligence for children with a below-average IQ level, serving a potential medical advantage. For Participant 10, HHGE could be utilised as a form of "corrective therapy" for children with a potential learning disability. Moreover, Participant 26 indicated that an individual's IQ level was "directly proportional to […] quality of life", in which a low IQ level corresponded with a reduced quality of life. In a similar argument, Participant 5 stated: "[G]ene editing should improve a quality of life. That should be the main goal. So, if […] you can improve someone with a low IQ to a normal spectrum, then it is great […]"

Conversely, "Where do we draw the line?" asked Participant 9. Most participants argued that it may be challenging to determine the ethical boundaries for such genome editing applications, in which the threshold for what is considered average intelligence would continue to shift, crossing a moral boundary.

> "And I think that when it comes to issues where the child might have a lower than average intelligence, I don't think that's something that we should maybe be messing with. Because then it's like, the line will keep getting pushed further and further as we go along, saying […] but what is the cut off for below average intelligence, because it might be a disagreement between this doctor and this doctor."

Thus, for Participant 9, it was necessary to curb the use of HHGE at health conditions. He emphasised:

> "[T]he main thing that has come up for me with gene editing is […] where do we draw the line? And I think for me […] I draw the line at diseases, you know. Because, in that instance […] it's a visible thing, we can see that we're improving someone's quality of life." (Participant 9)

In this respect, the use of genome editing for treating diseases would be ethically justified, considering its clear and positive impact on the health and quality of life of the prospective individual.

Moreover, the participants feared that permitting genome editing for enhancements could shift the focus from health-related concerns to enabling parents to design their children according to personal preferences or prevailing societal trends (Participant 16). Some participants noted the constantly evolving nature of such trends, which could result in continuous genetic alterations across generations to keep up with current trends. As participant 18 expressed:

> "[I]t could just lead to people going whatever's trending at that time, you know, whether it's, um, blue eyes, the next time it's gonna be brown eyes, in three years' time it's gonna be, um, curvy bodies, and the next one is, you know, it wouldn't end."

This may lead to increasingly bizarre or unusual genetic modification outcomes, aligned with societal trends. "Ok, blue eyes are in fashion, um, ten years down the line, you know, oh, let's make one blue eye, one brown eye, it's ridiculous," said Participant 7.

For most participants, such applications were overstepping moral limits and should be prohibited. In this respect, Participant 27 opined:

> "[I]n terms of using genetic editing for customisation, for designing people […] if you could say that, I never thought that I'd say that, but to design people, I still think that this, in this aspect, should be forbidden." (Participant 27)

*Commodifying human life*

The participants highlighted broader ethical issues which may be overlooked when permitting HHGE for genetic enhancements. They shared concerns that prospective children may be treated as mere objects of parental desire rather than individuals with intrinsic dignity. Thus, human life could potentially be commodified. Reflecting on this stance, Participant 27 emphasised that prospective children are not "a possession or property […] but these are actually people, living people." Participant 21 argued that the inherent value of being an "organic human being" would be diminished, specifically when said individuals are perceived as objects with customisable features.

> "[I]t gets into the realm of like designer babies. And then suddenly, you're not really seeing this child as a person anymore, but more so as like your little pet that you've designed exactly how you want it to look and stuff. So […] you won't see it as a person anymore, because like I chose how you look and that, so you're my little pet." (Participant 6)

Participant 6 articulated the concern that allowing parents to design their children could produce negative repercussions, such as the dehumanisation of said individuals.

The notion of designing children was likened to the parent assuming a divine role or acting as God, tampering with natural human development. "I think at this point, we're basically playing God," said Participant 9.

Moreover, some participants believed that the reduction of individuals to objects of parental desire could revive dangerous historical ideologies, such as eugenics. As Participant 26 stated: "[F]or things like skin tone and all of that, it might just be opening a door to things like eugenics." Parents may design their children to become the "most optimised human being", gravitating towards the creation of an ideal race (Participant 21). "You are basically trying to […] build your ideal person, your ideal human being," said Participant 9. The notion of designing an ideal person was akin to historic eugenic practices, such as selective breeding to create individuals with desirable characteristics. According to Participant 21:

> "It's […] such a whole Nazi eugenic type thing of, you know, breeding […] the perfect race, you know, and trying to customise your children to be the, you know, the most optimised human being you can get."

*Subtheme 6b. Nature vs Nurture*

*(i) The overlap between genes and the environment*

The personality or behavioural traits of an individual may be attributable to genetics or nature, however, most participants believed that environmental factors are also instrumental in the expression of genes. As such, genetic factors should not be considered in a vacuum, where the participants highlighted the intrinsic interrelation between genes and the environment or *nature* and *nurture*. According to Participant 6:

> "[S]ome people are predisposed to maybe being more aggressive or more empathetic, but I firmly believe that our personalities as a whole are more so shaped by our environment and the people we're around with, rather than our actual genetics."

In her opinion, whilst genetic composition may determine one's personality traits, this was not the only factor. These traits are primarily influenced or induced by one's surroundings or living environment (Participant 6). These are external factors which exist "outside of the genes [….] or an outside influence that then impacts on the individual, independent of what their genes are […]" (Participant 26).

Given this context, Participant 1 declared that genetically enhancing prospective children to possess certain traits may be "futile" considering the effect of said environmental factors. Moreover, Participant 6 added:

> "So even editing someone so that they're predisposed to be less aggressive, if they're in an environment where being aggressive is advantageous, or still going to end up being an aggressive person, and the gene editing won't change that."

Thus, individuals may adapt to the prevailing circumstances within their environment, which could result in the modification or suppression of their genetically inherited traits. Behavioural traits like aggressiveness may be developed or nurtured in an environment where it is a necessity or could prove beneficial.

Moreover, some individuals may display aggressiveness when exposed to an environment where aggression is the norm. As Participant 2 stated: "[Y]ou can get the […] nicest person, that if he is in an environment that is very aggressive, he will become more aggressive" Thus, the participants feared that gene editing may not completely negate the influence of environmental factors.

> "[Y]ou can influence the genetics, but there's still nurture, and nurture has a big impact on how your child grows up. So you might eliminate the genes, but whatever happens to the child when that child is growing up will also impact, so it might be a futile exercise." (Participant 1)

The participants also indicated that whilst genes establish the foundation for certain personality traits, it is the environment which ultimately refines or decides their expression. To illustrate, Participant 6 noted that certain personality traits may not completely manifest unless specific environmental "triggers" are present. She added:

> "And also, for personality disorders, some of them are triggered by trauma, so it's not something you're born with, it's something that you experience. So then, how would you distinguish that, oh, this person has BPD traits, but they never come up in their life, because they never experience the specific triggers that allow them to develop it further."

Thus, although some individuals may be genetically predisposed to personality disorders such as BPD, these characteristics may only become apparent when trauma is experienced. Thus, the Participant highlights the controversy in deciding whether certain traits are genetically inherited or acquired from life experiences.

*(ii) The essential balance between nature and nurture*

The participants emphasised that certain talents, such as intelligence, necessitate a balance between nature and nurture to be fully realised. Some argued that genetically modifying a child to be more intelligent may be pointless if not accompanied by specific extrinsic factors, including hard work. According to Participant 19:

> "But the difference […] from making a very intelligent baby is that, the child herself still has to do something to gain that advantage over the other children. So, they all still have to work hard, they still have to have a work ethic, they have to work hard to gain that advantage."

Thus, a child may be genetically inclined to be intelligent but would still require a learning environment which nurtures hard work and growth to ultimately attain success. Thus, intelligence is perceived as having both genetic and environmental influences in its expression. As Participant 6 stated: "[W]hile changing the talents can predispose the child to being more intelligent […] it isn't the only thing. So hard work also goes towards your intelligence […]"

Moreover, some participants feared that allowing parents to use genome editing to enhance their child's intelligence could diminish the significance of hard work. For the participants, intelligence was not valued for its natural presence alone, but the hard work and personal effort which accompanies it. As Participant 8 stated: "[W]hen it comes to being intelligent […] it all comes down to hard work, training, and basically studying and doing your best, putting in your own effort."

As such, participants felt that genetically modifying a prospective child's intelligence could reduce the motivation for hard work and personal achievement. According to Participant 19: "We do need hard work. So, if everyone is equally intelligent […] without hard work, then what incentive is there for people to work hard?" Thus, if individuals are genetically engineered to be super intelligent, they may not find the need to work hard or invest personal effort in achieving their life goals. In this respect, Participant 19 argued that "life becomes without purpose".

Furthermore, it could create the notion that success is based merely on genetic factors instead of hard work. According to Participant 8: "[K]ids should be taught to work hard to achieve their goals, not to be given the shortcuts in life […]" In her opinion, it was crucial for prospective children to learn that achievements were not simply handed to someone but are attained through hard work and immense effort.

For the participants, hard work was significant for its impact on various dimensions of an individual's life. Firstly, there is a level of personal accomplishment or satisfaction that emanates from achieving something through hard work.

> "[Y]ou have your achievements and stuff […] you feel proud of […] the *things that* you actually, you know, did. You feel happy […] You know, ok, I worked hard to get where I am today […]" (Participant 17)

Accordingly, achievements generated through personal effort invoke a deeper sense of fulfilment.

Secondly, hard work prompts a form of self-growth and intellectual development. This was articulated by Participant 10:

> "[T]he lessons learned from struggling a little bit through life and […] being forced to actually work hard at something and study something intensively, um, I think the lessons that you learned […] during that process, are part of what gives you the […] ideas and the […] new concepts that you may want to then, further research, in order […] to develop technology […] So I think that's, uh, a lot of where inspiration comes from, when you struggle […]"

One may acquire additional skills when driven by hard work and engaging in rigorous tasks. This could stimulate critical thinking and the development of innovative ideas or novel concepts vital for new discoveries. Thus, knowledge acquired from hard work is invaluable.

Lastly, individuals who attain success through hard work are valued differently in society and receive greater levels of respect. As Participant 20 expressed:

> "I have a respect for someone who went to varsity, like study and finishes her study, like, I have a respect, like, for the fight that they have put in, for the effort, and then for the time that is spent."

Thus, Participant 20 feared that if genetic enhancements for intelligence are permitted, it could also undermine the respect earned by individuals who work hard for their achievements.

### *(iii) "The great nurturing" is better*

For some participants, an individual's personality traits or talents could be cultivated naturally in a conducive environment, without the requirement for gene editing. Gene editing was considered "too extreme" to manage behavioural traits, such as aggressiveness (Participant 5). Participant 10 provided:

> "I think gene editing is possibly too far of an extreme thing to try and influence, uh, behavioural traits of a child. Obviously, there is part of that, that is nature, and part of that, that is nurture. Um, but I believe that the great nurturing, obviously, um, that's a much better way to go, uh, than using gene editing."

Accordingly, although both nature and nurture play a significant role in shaping one's behavioural traits, some participants preferred the natural route in personality development, or what Participant 10 described as, "the great nurturing". This was deemed a more suitable and less extreme approach than gene editing.

For example, Participant 8 described how certain environmental factors, including the correct upbringing or good parenting, could naturally impart certain characteristics in prospective children. She provided:

> "And with regards […] to personality traits, such as how aggressive or cooperative your child will be, I believe that those are values that a parents should instill in a child. A child is taught that, and a child is […] influenced by the example that is set for them."

Thus, setting a positive example for children or educating them on how to be less aggressive would be a better option than genetic modification or enhancements. As Participant 3 stated: "[W]ith aggression […] you can, like, teach someone to be less aggressive." Sharing a similar view, Participant 19 asserted:

> "I still firmly think that […] no application of this should be done in anything. Because people can be trained, people can learn […] They can be conditioned in society to not be like that."

As such, some participants advanced that educational efforts or societal influences could also encourage desirable behaviour, instead of using gene editing.

### *Subtheme 6c: The loss of genetic diversity*

The participants advanced a significant concern that permitting HHGE for enhancements could have severe repercussions for genetic diversity, which was vital for the well-being of society. As Participant 26 stated: "[I]t might also have a negative influence on the diversity that is already apparent in our world." As such, it was important for most participants that gene editing applications be prohibited to preserve said diversity. "[W]e need diversity, and that's very important, so we all voted no," said Participant 22.

### *(i) Homogeny and lack of individuality*

The participants outlined various ways in which HHGE applications could have detrimental effects on genetic diversity. To begin with, most participants shared the concern that widespread applications could eventually result in individuals who are identical or homogenous. To elucidate this point, Participant 11 provided:

> "I would have to disagree also, because it means […] we'll have less diversity, like between people. There'll […] be just like one kind of people, like, we are all just the same in skin colour, same kind of eyes, same kind of body parts and whatever."

Accordingly, it could lead to a homogenous society in which prospective parents select genetic modifications that align with societal trends or emulate looks that are in fashion. As Participant 19 indicated: "[S]o if we had to have the choice of […] how people should look, eventually people would start looking very similar because that would go according to trends." For Participant 18, this was similar to creating a "zombie society", where everybody has the same physical characteristics and behavioural traits, losing their individuality.

> "I feel like we gonna be […] made into like a zombie society […] We all gonna just be one thing […] So […] it's gonna lose that […] individualism from people, whether you're aggressive or cooperative […] let it be your own individual thing rather than we all wanna be made cooperative, or […] aggressive […]" (Participant 18)

As a result, some participants feared that permitting gene editing applications for enhancements, with the capacity to produce similar individuals, could diminish the intrinsic human value of being unique. As Participant 8 emphasised: "All five fingers are not the same. That's what makes us human. That what […] makes us diverse and different […] if everybody's gonna be the same […] how are we gonna be different?"

Thus, the concept of individuality or uniqueness is derived from the reality that everybody differs in physical appearance, personality and the possession of talents (Participant 1). Participant 17 expanded on this point, stating:

> "[W]e are all meant to be, um, our own person. We can't actually all be the same. We all have our strengths, and we all have our weaknesses […] some of us […] are not […] good in academics. Some of us are not good in […] athletics. Some of us just don't like sport. Some of us wanna focus more on education than sport."

As such, each individual is intended to be unique or different, possessing a distinct set of virtues and weaknesses. For Participant 9, this diversity was a crucial component of the "human experience" that needed to be protected. He expressed:

> "The *difference* […] between individuals, I think, is something that we have to preserve. And […] I think it's […] something that makes […] life worth living, you know, when you get to interact with different people who have different *characteristics*." (Participant 9)

Engaging with people of diverse characteristics was associated with the many joys of existence, enabling a less mundane and more enriching life experience (Participant 15). "When it comes to diversity, I have to agree also that, uh, the world will be boring [if] we are all intelligent," said Participant 4. Thus, some participants felt that the world would be monotonous if everyone were on the same level or equally intelligent.

Participant 19 provided additional insights, discussing the aesthetic appeal of diversity. She stated: "[D]iversity is very beautiful to behold. So […] sometimes you see a person with this texture of hair or this skin colour and […] it's just so beautiful to witness and see." For Participant 23, such physical attributes also reflected one's cultural heritage. Consequently, she feared that gene editing applications for aesthetics (such as skin colour) could eventually decrease "cultural diversity".

Several participants also voiced concerns regarding the impact of such genetic modifications on certain talents. If everyone were genetically modified to reflect similarity, there would be no people with unique capacities or talents. As Participant 29 stated: "It just […] erases talent, there won't be talent in the world. We won't be able to celebrate talent, like FIFA World Cup, that's […] us celebrating talent." Thus, these abilities would no longer be considered talents but ordinary skills (Participant 25).

*(ii) Societal imbalance*

Diversity was not only aesthetically pleasing but served multiple functions in society. Participant 2 elucidated that individuals with varying levels of intelligence add different dimensions to society, occupying unique roles.

> "[S]o far, we've had our intelligent people doing the things that they need to do to improve humanity, and that's why we have gene editing. And the less intelligent people doing what they

> need to do to improve humanity, where they work in the areas that the more intelligent people don't need to waste their time on, and you need that diversity." (Participant 2)

Similarly, Participant 25 observed that intelligence is often associated with an introverted character, suggesting that such individuals may lack the specific social skills commonly found in extroverts. However, introverts tend to excel in critical thinking. Therefore, he emphasised the unique roles that introverted and extroverted individuals play in society.

> "I do think that there is some benefit to […] having introverts and extroverts in society, you know. Introverts tend to, to think more critically about certain things, and I do think they add value to society, and extroverts also do the same thing." (Participant 25)

Thus, the proper functioning of society requires a balance of diverse skills and abilities, each contributing uniquely to its progress. Genetic enhancements aimed at increasing intelligence or other traits could disrupt this balance.

Consequently, the participants shared a concern that gene editing for specific talents or behavioural traits could reduce other valuable attributes essential for maintaining societal balance.

To illustrate, Participant 16 indicated how increased intelligence through genetic enhancements could generate a surplus of individuals pursuing a similar career path. He added:

> "I think every parent wants their child to be a doctor and, uh, you know, a doctor, a scientist and all of them, mathematician. Now, um, if parents are given this choice, no one's gonna say no, but I want my child to be a musician, then we don't have music, then we don't have anything that's like keeping the world beating. We don't have the odds, we don't have anything else […]"

In his opinion, prospective parents may opt for the higher end of the spectrum when selecting genetic enhancements to ensure that their children pursue careers in prestigious fields, such as medicine or science. As a result, other esteemed fields like music may decrease due to fewer individuals selecting this career path. For Participant 16, these fields contribute to our societal diversity, including the quality and vibrancy of human life.

### *(iii) Genetic trade-offs*

Prospective parents may genetically enhance their children to have desirable behavioural traits whilst losing other valuable or impactful ones. According to Participant 26: "[S]ome of the personality characteristics that we deem as undesirable […] do actually have an advantage out there, in the real world.”

For example, Participant 22 indicated that removing the gene for aggressiveness may potentially be “removing competitiveness”, which was advantageous for sports or succeeding in academics.

> “I feel like if we […] remove aggressiveness, um, we’ll also be removing competitiveness, and that’s going to have a very large aspect on, um, our social structure. So for sports, especially, um, if you’re not aggressive or competitive in sports, you can’t do much […]” (Participant 22)

He added further:

> “[E]specially in school, when you’re competing against your peers […] if you’re not competitive there, you don't have that drive to get better than the other person. Um, you can be very intelligent, but you […] won't use it. You won’t […] feel the need to push forward to […] be better than other people.”

As such, genetic modifications to remove aggressiveness may reduce the child’s competitiveness. This is substantial for individuals with athletic tendencies, potentially hindering the child’s ability to excel in sports. Furthermore, removing competitiveness could inhibit one’s motivation to succeed and outperform others in academics. Ultimately, the participants acknowledged the broader societal impact, in which removing aggressiveness could reduce the number of competitive individuals or those driven to succeed in various aspects of life.

Similarly, Participant 26 indicated that genetic enhancements for increased cooperativeness may affect an individual’s ability to be disagreeable or assertive. He emphasised: “[I]f a person is disagreeable, for example, those have functions in terms of society. We know that disagreeable people […] are more likely to be assertive.” Therefore, whilst disagreeableness may be perceived negatively by certain parents, it is also associated with being assertive. According to Participant 26, assertiveness enables people to be “individualistic” and pursue exclusive life paths. Participant 9 also indicated: “Some of the greatest discoveries have come with people going against everything else that they know,” or being less cooperative. Thus, participants feared that altering these traits could have certain drawbacks for society, such as reducing individuals who were essential catalysts for societal innovation and advancement.

### *(iv) Diversity and survival*

A few participants also highlighted the significance of diversity in determining how society responds to health crises. In the context of the COVID-19 pandemic, Participant 19 observed that countries which were "very homogenous were the ones where people died the most." She added:

> "[I]n my opinion, you know […] the Euro-European countries, um, where […] you don't get a lot of diversity and what not […] you could see […] it's easy to pass it on because they're very similar, and they will respond in a very similar manner to […] the virus […] And you could see in […] places like, um, Johannesburg, despite it being very congested like, I live in Johannesburg, it's very congested here […] you expect it […] to spread much faster and kill much more people, but because of the diversity that is here in Johannesburg, I mean, people are not dying as much as they are in Cape town where people live much far away from each other and what not […] Skin colour could just look like it's just skin colour, and eye colour and hair colour together, but they could […] be markers for other things as well."

In her opinion, the existence of diversity serves a broader function for society. It ensures the adaptability and survival of populations against deadly viruses which may target a "specific genotype", potentially eliminating individuals who share those characteristics (Participant 3). Thus, genetic variation enables different responses to environmental conditions, safeguarding entire populations from extinction when confronted with a deadly virus.

### *Theme 7: Ambiguity in reasons for opinion changes*

Theme 7 investigated the reasons behind participants' opinion changes observed during the study, focusing on changes resulting from arguments raised in the deliberative discussions. These changes were tracked to see if they persisted one week after the deliberations. While the quantitative data recorded significant opinion shifts, the analysis could not yield sufficient evidence to identify compelling arguments or specific factors responsible for these shifts. A key challenge was inconsistencies between the quantitative and qualitative data, which complicated efforts to establish definitive conclusions. Moreover, even in instances where the data sources aligned, the participants did not provide clear explanations for opinion changes, and speculation was avoided.

*Subtheme 7a. Inconsistencies between quantitative and qualitative data*

This subtheme captures instances where the data in the public opinion polls or surveys (quantitative data) did not correspond with or match the textual data provided in the transcripts (qualitative data). To illustrate, some participants shared perspectives that were different when compared to their original opinions recorded in the opinion polls. In the pre-survey (before the deliberations), Participant 1 indicated that she would use genome editing for asthma and eczema (P2), subject to conditions. Conversely, when asked the same question in the deliberative discussions, she expressed an unconditional 'yes', presenting a strong argument for genome editing in this particular case. According to the textual data:

> "Ok, so let's go to the second question, the second question is now, is it ok to do it for less serious illnesses for example […] asthma or eczema? Is it still ok, do you feel the same or does your view change a little bit? Participant 1, let's start with you." (Facilitator)
>
> "As a mom, that had a child with asthma, asthma can come in varying degrees so it can develop into a very serious issue, so from that stance, I totally agree. With the eczema topic, same thing, I have eczema myself. It can be very terrible, it can be localised, but in general if you can fix it, then why not?" (Participant 1)

Thus, the participant did not discuss her original opinion (being yes, subject to conditions) as documented in the survey data prior to the deliberations. Moreover, being the first to provide her opinion on less serious heritable diseases in the first sub-group discussion, she altered her viewpoint before listening to any preceding arguments presented by other participants. It can only be deduced that a change in opinion occurred prior to the deliberative discussions, for reasons that cannot be attributable to the study itself.

Similarly, Participant 5 supported genome editing applications for disabilities, subject to certain conditions, as per the survey data. However, during the deliberative discussions, she strongly advocated for the unconditional use of genome editing in this regard. She stated:

> "I think with disabilities, any and all disabilities should be gene edited. Because you can't say if someone has the, not a really bad disability, he can go and have medical treatment for that, that is not to say that that guy can afford it and that is traumatic. Why do you want to put him through trauma if you can change that disability? Disabilities, let's, if you can gene edit them and help them, I will edit everything."

Accordingly, while a change in opinion is evident, the participant did not elaborate on her pre-survey stance or provide clarity on why her opinion had changed. It remains unclear as to whether her reasons for now were influenced by the deliberative discussions or if the change predated these discussions.

In a similar vein, Participant 10 initially said ‘no’ to genome editing for albinism (P4) in the pre-survey but presented his opinion as ‘yes, subject to conditions’ during the deliberations as his original stance. As he provided: “I believe it should be allowed, based on certain conditions, you know.” This discrepancy between pre-survey and deliberation data suggests his perspective had already shifted prior to the discussion. However, even if attributable to arguments presented in the deliberations, there is no clear indication.

These patterns were also prevalent in the discussions on serious infectious diseases like TB and HIV/AIDS. For example, in the pre-survey, Participant 6 opined, ‘yes, subject to conditions’ for TB and HIV/AIDS, but had indicated an unconditional yes for both applications in the deliberative discussions. For TB, she stated: “Yes, I agree fully, and I think it’s important […]” However, this opinion did not align with her original perspective and further highlights inconsistencies between the data sources. This was a recurring pattern in the study, where participants often did not carry their original perspectives recorded in the pre-surveys to the deliberative discussions. This inconsistency creates difficulty in understanding the reasons behind their opinion changes. Without a clear grasp of participants’ initial stances, it becomes challenging to identify the factors influencing these opinion changes.

Secondly, while several participants discussed their original pre-survey perspectives during the deliberations, their subsequent changes in opinion (reflected in the post-survey data) were not documented in the textual data. To illustrate, Participant 15 initially provided an unconditional ‘yes’ for genome editing for the flu or common cold (P9) in both sub-group discussions. However, in the post-survey, she changed her opinion to ‘yes, subject to conditions’. Even if the deliberative discussions had influenced her change in opinion, there is no explicit evidence in the transcripts or textual data to support this finding.

Thirdly, in instances where the participants explicitly stated that they had changed their viewpoints, this was not supported by the survey data. According to Participant 18:

> “Since hearing Participant 7 and Participant 14, I’m kind of changing my position, but I was more on I disagree because I feel like asthma and eczema are things that are more treatable so there is like treatment, even though it doesn’t sometimes go away completely but it’s something that you can manage whilst living, but I get that there are some extreme cases […] I will say with conditions for extreme cases.”

Notably, the pre-survey data revealed that Participant 18’s opinion remained constant with no evident changes for P2. Thus, such inconsistencies presented heightened challenges in understanding the factors influencing these shifts.

# *CHAPTER 5*

## *SUMMARY OF FINDINGS AND CONCLUSION*

### I INTRODUCTION

The objective of this qualitative analysis study was to understand the perspectives of a South African informed public regarding acceptable HHGE applications for genetic health conditions, immunity and genetic enhancements. Following the results of the thematic analysis conducted in the study, a global theme emerged from the data, namely, 'Balancing health benefits (including improvements to the quality of life) with unanticipated risks to individuals and society.'[1323] The results reported seven principal themes which responded to the research questions outlined earlier. These included: 'The potential benefits of HHGE', 'impact on natural immune responses', 'equitable access to HHGE for everyone', 'HHGE and discrimination in society', 'the right to autonomy', 'going against human nature' and 'ambiguity in reasons for opinion changes'.

### II SUMMARY OF FINDINGS

*SRQ 1: What is the informed South African public perspective on the use of HHGE to prevent genetic health conditions?*

SRQ 1 was addressed by the following themes:

- Theme 1: The potential benefits of HHGE
- Theme 3: Equitable access to HHGE for everyone
- Theme 4: HHGE and discrimination in society

*Theme 1: The potential benefits of HHGE*

Given the potential therapeutic benefits of HHGE for prospective individuals, the informed South African public favoured the use of genome editing to prevent genetic health conditions that were adequately severe.[1324] Theme 1 was divided into two subthemes, which addressed:

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[1323] See Thaldar et al op cit note 92 at 12.

[1324] Ibid at 13.

(a) Benefits for the prospective individual; and (b) Benefits for society. When discussing genetic health conditions, the participants primarily emphasised *the potential benefits for prospective individuals*. Several participants did highlight the positive impact that genome editing could have on public healthcare (benefits for society); however, this argument received greater support for *serious infectious diseases* discussed in SRQ 2.

*(a) Benefits for the prospective individual*

In the context of genetic health conditions, participants accentuated the potential benefits for prospective individuals, such as *the prevention of serious genetic health conditions*. For the participants, the severity of the health condition was a crucial component in determining the use of HHGE for each policy proposal.[1325] This correlation was documented in prior research, revealing a strong nexus between support for therapeutic applications of HHGE and the severity of the condition.[1326] Disease severity often played a decisive role in public acceptance or disapproval of genome editing applications.[1327] In the current study, the severity of the disease was characterised by, firstly, its *life-threatening* potential or, secondly, its ability to impact the *quality of life* of the prospective individual. According to the participants, the diseases presented in P1 (sickle cell anaemia, muscular dystrophy, or Alzheimer's) were inherently or intrinsically life-threatening, securing substantial public support. Similarly, considering the argument that asthma (P2) could manifest in "varying degrees" (Participant 1), most participants agreed that it could become life-threatening for certain individuals, warranting conditional HHGE applications. On the contrary, participants contended that eczema (P2) was a relatively mild condition and could be effectively managed with medical treatment. These observations align with prior studies, including the AP-NORC study, where 67% of Americans supported the use of HHGE to decrease the risk of potentially life-threatening health conditions, like cancer.[1328] Similarly, a global online survey revealed that out of 10, 067 respondents, roughly 63% agreed that HHGE should be used to prevent life-threatening diseases, while approximately 12% objected.[1329] Notably, the South African participants also favoured the use of HHGE for conditions that were life-threatening due to environmental or external factors. In this respect, genome editing for albinism (P4) received conditional support. For some participants, albinism was not inherently life-threatening,

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[1325] Ibid at 12.

[1326] Jedwab et al op cit note 356, Hoffman-Andrews et al op cit note 356; Segers op cit note 356.

[1327] Ibid.

[1328] Thaldar et al op cit note 92 at 4.

[1329] McCaughey et al op cit note 357.

enabling such individuals to lead normal, healthy lives. Conversely, the participants began to recognise the broader health implications of the condition due to certain environmental and social factors. Participants observed that melanin deficiencies associated with albinism could elevate the risk of developing life-threatening health conditions, such as skin cancer, when such individuals are exposed to excessive sunlight. Moreover, African albinos were often killed due to superstitious beliefs and cultural practices surrounding their physical appearances. Consequently, albinism was considered life-threatening as a result of environmental and social factors present in South Africa. These findings corroborate Thaldar et al's assertion that perceptions of disease severity vary across different countries and are contextually determined.[1330] To illustrate, Kromberg and Kerr's research revealed that albinism was relatively common in the South African region, with an approximate prevalence rate of 1 in 3900 as compared to Europe, North America and Asia.[1331] According to Cohen et al, skin cancer was frequent among people with albinism in South Africa and was reported as the leading cause of death for African albinos.[1332] Moreover, people with albinism in African countries were often targeted due to ritual killings, with 515 attacks and 190 murders recorded between 2006 and 2017.[1333] As such, it can be deduced that the participants in the study viewed albinism as a severe health condition due to these contextual factors in South Africa, in which the results may vary in other countries.

Secondly, the severity of the health condition was evaluated against its potential impact on quality of life. Similar to other studies, the South African informed public supported the use of HHGE to prevent not only life-threatening but also debilitating health conditions.[1334] This support was aimed at enhancing the overall quality of life of affected individuals and their families by preventing the inheritance of serious genetic health conditions. The argument that genome editing could be utilised to improve the quality of life is frequently cited in the literature.[1335] For instance, Hendriks et al reported similar findings among the Dutch public, where support for genome editing stemmed from its potential to enhance the quality of life of prospective individuals and their families.[1336] Similarly, a core recommendation from a

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[1330] Thaldar et al op cit note 92 at 14.

[1331] JGR Kromberg & R Kerr 'Oculocutaneous albinism in southern Africa: Historical background, genetic, clinical and psychosocial issues' (2022) 11 *African Journal of Disability (Online)* 1–7 at 3.

[1332] Kromberg & Kerr ibid at 2; MC Herbst 'Fact sheet on Albinism and its Implications' (2015) *Cancer Association of South Africa* available at https://cansa.org.za/files/2021/01/Fact-Sheet-on-Albinism-and-its-Implications-January-2021.pdf, accessed on 05/072024.

[1333] Kromberg & Kerr ibid at 5.

[1334] McCaughey et al op cit note 357; Sawai et al op cit note 367.

[1335] I van Dijke et al op cit note 360 at 1779.

[1336] Hendriks et al op cit note 361 at 6, 7.

citizens' jury in Australia was that genome editing could "alleviate human suffering", improving the quality of life for individuals.[1337] Conversely, the American general public did not share this vision.[1338] According to the PEW Research Center, 40% believed that the widespread use of HHGE would not impact quality of life, while 18% were afraid that it could become worse.[1339] However, the South African informed public suggested otherwise, emphasising the challenges and limitations that prospective individuals and their families may experience if certain genetic conditions are left untreated. Fundamentally, the participants believed that one's well-being and the capacity to lead a normal and fulfilling life should take precedence when considering genetic health interventions.

In declaring their support for HHGE, participants pondered the daily challenges that prospective individuals with certain genetic conditions may encounter, including impairments in daily functioning, which impact both physical and psychological well-being. Participant 7 drew attention to the close relationship between physical and psychological well-being, noting how serious conditions like sickle cell anaemia (included in P1) may not only cause physical pain and suffering but also lead to a decline in mental health. Thus, genome editing is perceived as a valuable tool in safeguarding the physical and psychological well-being of prospective individuals, particularly in cases where conventional medicine provides minimal alleviation. Moreover, several participants expressed concern over the severity of Down's syndrome (P5), in relation to its effect on the cognitive and intellectual capacity of prospective individuals. For Participant 26, this corresponded with a "poor quality of life".

In conjunction with these concerns, the participants underscored the potential impact of particular health conditions on the social and financial well-being of prospective individuals and their families. The participants collectively acknowledged that genetic health conditions like disabilities (P3) or Down's syndrome could impose significant limitations on the ordinary life activities of affected individuals. Several participants emphasised that these conditions may prevent prospective individuals from reaching basic life milestones, such as independence, securing employment or establishing a traditional family life. Additionally, one participant highlighted the specific impact on families or caregivers, indicating that more severe cases of Down's syndrome may necessitate lifelong care. Her support for HHGE was grounded in the concerns she raised about the long-term self-sufficiency and independence of affected

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[1337] Nicol et al op cit note 362 at 20.
[1338] Pew Research Center op cit note 363.
[1339] Ibid at 75.

individuals, in the absence of their caregivers. Similarly, Participant 25 stressed the importance that HHGE be used to ensure that prospective individuals are able to maintain a sustainable livelihood, which was the determining factor in his approval of the technology. On the contrary, Participant 3 emphasised that individuals with Down's syndrome may still experience employment barriers in South Africa due to a lack of job opportunities that leverage their unique abilities. This contributes to the overall difficulty in achieving independence and financial stability for these individuals, suggesting that societal structures need to be more inclusive. However, addressing this issue extends beyond the primary objectives of genome editing technology and this dissertation.

The discussions extended to the financial implications of living with certain health conditions and the potential financial strain on prospective individuals and their families. To illustrate, some participants examined the economic impact of medication dependency, indicating how serious heritable diseases often require constant medical treatment. They stressed that such treatment could become a substantial long-term expense for prospective individuals and their families, impacting their financial well-being. In this context, Participant 9 evaluated the affordability of managing a chronic condition like diabetes, specifically noting the high cost of the required insulin doses. In his view, this was not affordable to the "average family". Significantly, while less severe conditions like asthma and eczema can often be managed with treatment, several participants considered the potential high costs involved in accessing such care. For example, Participant 9 noted the cost of purchasing asthma pumps, indicating that these regular treatments are not affordable to everyone.

These financial considerations also encompassed more complex needs, such as access to specialised education. Prospective individuals with disabilities or Down's syndrome would require tailored learning environments, such as special schools, to support their unique developmental and educational needs. As a result, the participants expressed concern that these requirements could place a significant financial strain on prospective parents. Moreover, the disparity in financial resources among different families means that some families may struggle to afford access to special schools, potentially limiting their children's educational opportunities (Participant 4). In addition to financial concerns, Participant 5 emphasised the limited disability-friendly infrastructure in South Africa, including a shortage of special schools. Consequently, the shortage of special schools in South Africa would result in a growing number of children awaiting admission, leaving them without immediate access to education.

For the abovementioned reasons, the participants accentuated the need to utilise gene editing technology to enhance the quality of life of prospective individuals, ensuring that they are able to lead normal and fulfilling lives. The intended purpose of the genome editing application was thus significant in their approval of the technology. Similarly, a Japanese study demonstrated that acceptance of HHGE applications was higher when aimed at treating or preventing life-threatening or debilitating diseases.[1340]

On the contrary, while influenced by objective factors (such as the cost of treatment), quality of life is also shaped by a level of subjectivity.[1341] The literature reveals that quality of life is often perceived more positively by individuals with chronic illnesses and disabilities than by their families, healthcare providers and the general public.[1342] Thus, while enhancing the quality of life serves as a key rationale for advancing towards genome editing technology, as demonstrated in this study, the adverse impact of serious health conditions on quality of life is frequently overstated by individuals who do not experience these health conditions.[1343] This difference in perception highlights a cognitive bias, in which affected individuals often report a higher sense of fulfilment or quality of life than anticipated by said others.[1344] Although this study consisted of a diverse participant pool, it did not focus on the first-hand perspectives of individuals currently living with serious health conditions, in which case, the results may differ. As such, future research should address these gaps, emphasising the voices of individuals currently living with chronic illnesses or disabilities in South Africa to develop a greater understanding of their lived experiences and self-perceived quality of life.

Interestingly, biomedical researchers emphasise an ethical imperative to explore measures like genome editing.[1345] The treatment or prevention of genetic health disorders to alleviate suffering is grounded in bioethical values such as beneficence and nonmaleficence.[1346] While this study does not explore the extent to which participants' responses align with these values, it is essential to consider their ethical implications in future research.

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[1340] Sawai et al op cit note 367 at 11.

[1341] Hoffman-Andrews et al op cit note 356 at 11.

[1342] Ibid.

[1343] Ibid.

[1344] Ibid.

[1345] JH Evans 'Setting ethical limits on human gene editing after the fall of the somatic/germline barrier' (2021) 118(22) *Proceedings of the National Academy of Sciences* 1–7 at 3.

[1346] Ibid.

### *Theme 3: Equitable access to HHGE for everyone*

Equitable access to HHGE technology for everyone was recognised as a fundamental value in the study.[1347] The South African informed public supported the use of HHGE for serious health conditions, provided that equitable access to the technology for everyone is made a reality. Theme 3 was divided into two subthemes, which addressed: (a) Financial barriers and active government intervention; and (b) Governmental challenges in ensuring equitable access.

#### *(a) Financial barriers and active government intervention*

The participants expressed concern that HHGE would not be equally accessible to everyone once made available to the general public. They highlighted issues in relation to the cost-effectiveness of the technology and potential financial barriers which could impede access for low-income or impoverished individuals. According to Participant 10, this could rear a society in which the affluent benefit from advanced technologies, like HHGE, while the poor are left to contend with diseases. Participants believed that such disparities could aggravate the existing divide between the rich and poor, a socio-political concern frequent in the literature.[1348] This concern aligns with the *fundamental cause theory* in public health doctrine, which can be used to understand how access to advanced technologies (like HHGE) could perpetuate existing health inequalities by primarily benefiting the wealthy.[1349] Moreover, the potential for heightened inequalities has been canvassed as an "acute risk" by several academics, precisely in countries like South Africa, where the division between the rich and poor is particularly stark.[1350] In this regard, some scholars believe that the potential negative consequences (such as heightened inequalities) provide a compelling argument against the use of HHGE altogether.[1351]

Significantly, notwithstanding the validity of these concerns, the South African participants did not find merit in prohibiting HHGE applications, nor did said concerns impact their acceptance of the technology. To illustrate, while equitable access was an important value, participants did not advocate for it as a precondition to genome editing becoming publicly accessible. They asserted the need for active government intervention in ensuring equitable access to HHGE for everyone; however, alongside the public availability of the technology.

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[1347] Thaldar et al op cit note 92 at 12.

[1348] Almeida & Ranisch op cit note 378 at 7; Brokowski op cit note 402 at 116.

[1349] Subica op cit note 403 at 877.

[1350] Shozi & Thaldar op cit note 404 at 43.

[1351] Ibid.

For Participant 14, it was crucial that the government not merely regulate the use of the technology but also lead the initiative in such genetic innovations. In his opinion, the South African government should adopt a more proactive approach in fostering intellectual property development and directing resources toward future research initiatives. Consequently, the participants remained optimistic about future (if any) HHGE applications, where potential socio-economic inequalities, although significant, did not alter their view of the technology.

In working toward the eventual accessibility of the technology to all, the participants suggested two strategies that the government could implement. Firstly, they should prioritise accessibility to serious health conditions first, especially in the context of limited healthcare resources. Participants expressed concern that less serious health conditions, if given precedence, may detract from the focus on more severe diseases. Thus, as with the current literature, disease severity was decisive in various aspects of the study, including the allocation of healthcare resources to ensure equitable access.[1352] The consensus was that genome editing for less serious conditions, such as asthma or eczema, should only be available once more critical health conditions have been adequately addressed. Moreover, government budget constraints may initially restrict funding to serious health conditions, with the expectation that, as resources permit, HHGE will gradually be made available for all genetic health conditions over time (Participant 22). Some participants provided further insights on how access should be regulated based on disease severity. One participant proposed that the severity of the condition should be assessed against clear criteria for eligibility, where HHGE is only accessible to prospective individuals medically diagnosed with serious health conditions. The use of such evaluation methods would prevent the misuse of the technology and ensure that serious health conditions are given first preference (Participant 27). This view was reinforced by Participant 29, who suggested that the government should conduct additional research (akin to this study) to garner public perspectives on which diseases should be classified as serious, thereby informing the allocation of healthcare resources. As such, a research-driven approach should be adopted to determine which specific health conditions should be prioritised. Moreover, it is important to note that this study only provided examples of potentially serious diseases and did not encompass a comprehensive list. As such, additional research in this regard would be advantageous for future (if any) HHGE applications.

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[1352] Jedwab et al op cit note 356, Hoffman-Andrews et al op cit note 356; Segers op cit note 356.

In their second strategy, the participants suggested a targeted approach which focused on enabling accessibility for low-income or poor individuals. Accordingly, the government should provide financial support to individuals who cannot access genome editing due to financial barriers. In this way, genome editing would be made accessible to both the wealthy and marginalised societal groups. To aid this process, Participant 4 advanced an eligibility criteria to assess the *financial capability* of each individual– being a significant component– before government subsidisation is provided. Thus, access to genome editing should be qualified, as based on financial capacity or certain socio-economic factors, before HHGE is made accessible.

*(b) Governmental challenges in ensuring equitable access*

While participants acknowledged the cruciality of governmental intervention in enabling equal access, several raised concerns about their ability to effectively implement the abovementioned strategies, given existing resource constraints. The participants shared mixed views on the role of governmental intervention in ensuring equitable access to HHGE, particularly in light of socio-economic and infrastructure challenges in South Africa. Participant 10 emphasised the government's struggle to deliver even basic necessities. This resonates with media and community reports in 2009, which highlighted significant shortcomings in public healthcare institutions, where basic care standards and patient needs remain unfulfilled.[1353] As a result, public trust in healthcare systems has declined.[1354] Accordingly, the participants feared that enabling equal access to novel technologies (such as genome editing) would present a heightened difficulty in South Africa due to said challenges. Moreover, considering the current pressure on public healthcare resources and increased demand for medical services (Participant 25), it would require additional resources that may not be readily available. This sentiment is consistent with the literature, which emphasises the difficulties in introducing new, cutting-edge technologies in low-resource settings.[1355] As a result, some participants indicated support for a collaborative approach, advocating for the involvement of both private and public healthcare to make HHGE accessible to all. In particular, Participant 23 stated that depending exclusively on public healthcare could lead to long waiting periods and delayed service

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[1353] WT Maphumulo & BR Bhengu 'Challenges of quality improvement in the healthcare of South Africa post-apartheid: A critical review' (2019) 42(1) *Curationis* 1–9 at 1.

[1354] Ibid.

[1355] S Goolab & J Scholefield 'Making gene editing accessible in resource limited environments: recommendations to guide a first-time user' (2024) 6 *Frontiers in Genome Editing* 1–18 at 1.

delivery, a problem already evident in public healthcare.[1356] Thus, the private sector may have the necessary resources and expertise to help fill the gap and facilitate access to HHGE (Participant 26). While collaborative efforts may be essential to overcome resource constraints and improve access to health innovations, further research would be necessary to investigate the practical aspects of such partnerships, precisely in low-resource environments. Additionally, as to whether it can, in fact, improve health equity for potential HHGE applications.

*Theme 4: HHGE and discrimination in society*

Several participants raised concern that HHGE could increase stigma towards disabilities and individuals currently residing with those conditions. Despite the potential to exacerbate societal discrimination, the South African informed public displayed continued support for potential HHGE applications. This owed to the argument that the purpose of genome editing was not to reinforce discriminatory ideals, but to promote societal well-being through disease prevention. Theme 4 was divided into two subthemes: (a) Negative impact on societal acceptance; and (b) The objective to improve societal well-being.

*(a) Negative impact on societal acceptance*

Resembling the critiques offered by particular scholars, some participants feared that applying HHGE to eliminate disabilities or other genetic conditions could exacerbate societal prejudices and discrimination against current individuals with those conditions.[1357] Thus, it could potentially reduce societal acceptance of "non-conventional" persons (Participant 25) and produce a negative impact. These assertions give credence to the expressivist critique, asserting that the use of genome editing to prevent certain disabilities conveys a pessimistic view of the condition and individuals living with it.[1358] In support of this view, Benjamin argued that such practices could perpetuate societal beliefs that disabilities are inherently negative and should be avoided. [1359] Moreover, resulting in a society in which people with disabilities are devalued.[1360]

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[1356] Maphumulo & Bhengu op cit note 1353 at 2.

[1357] Gyngell, Bowman-Smart & Savulescu op cit note 395 at 517; Nordberg & Antunes op cit note 395.

[1358] Gyngell, Bowman-Smart & Savulescu ibid at 517.

[1359] Benjamin op cit note 396 at 53.

[1360] Ibid at 53.

### *(b) The objective to improve societal well-being*

Although the aforementioned arguments hold merit, most participants rebutted by stating that the purpose of HHGE was not to heighten discrimination, but to ultimately promote the health and well-being of society by preventing health conditions that have a severe impact on human life. This aligns with the objections raised by some academics against the expressivist critique, who posited an underlying health-focused initiative driving potential genome editing applications.[1361] In their view, HHGE was conceived to address health issues without making value judgements about the disabling condition or the individual living with it.[1362] Similarly, Savulescu contended that opting to prevent or avoid specific health conditions should not be interpreted as discrimination or the devaluing of said individuals.[1363]

Rightly so, the South African informed public asserted that the potential impact of HHGE on societal acceptance should not overshadow its initial purpose to improve the quality of life. Similarly, the Nuffield Council was explicit in its rejection towards the expressivist critique, on the grounds that these were genetic conditions which severely impacted both the quality of life and life expectancy.[1364] According to Participant 11, it was about acknowledging the daily hardships experienced by individuals living with these conditions and using genome editing to mitigate these challenges. Importantly, Participant 19 accentuated the element of 'empathy' as a motivating factor behind such genome editing procedures. This involved the understanding that people with disabilities or other health conditions were in an unfavourable position compared to others. As such, HHGE was perceived as a means to address this imbalance for future generations, rather than upholding discriminatory ideals. For Participant 21, it would be unjust to deny a prospective child medical treatment (such as genome editing) on the grounds that it could foster discrimination. From his standpoint, these were separate societal issues that needed to be addressed by society itself, rather than shifting the responsibility to the prospective child. Therefore, despite the common sentiment across studies that HHGE could fuel societal discrimination,[1365] the South African informed public believed that this was an isolated matter which should not be conflated with the intended purpose of the technology.

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[1361] Almeida & Ranisch op cit note 378 at 10.
[1362] Ibid.
[1363] Ibid.
[1364] Gyngell, Bowman-Smart & Savulescu op cit note 395 at 517.
[1365] Delhove et al op cit note 394.

Informed by her lived experience with hearing disability, Participant 6 stressed that societal acceptance remains a pressing issue, notwithstanding educational initiatives to increase societal awareness. In her opinion, these were social challenges that would endure regardless of attempts to implement genome editing or not. In this regard, she maintained her support for the use of the technology. Similarly, Participant 22 suggested that, given the absence of strong objections in the study, public opposition to HHGE is unlikely in the current context. However, should objections arise, he proposed that educational initiatives highlighting the benefits and drawbacks of HHGE could aid in reassessing its appropriateness. On the contrary, although a diversified sample pool was selected, the findings of this study did not intend to be representative of the South African population.[1366] Future research could capture a wider range of perspectives to ensure that the findings are generalisable to the larger population. Additionally, public opinion may evolve over time as the technology advances. Regarding educational initiatives, it may be interesting to evaluate the impact of specific educational methods on public understanding and acceptance of HHGE for future research.

*SRQ 2: What is the informed South African public perspective on the use of HHGE to enhance immunity against infectious diseases?*

SRQ 2 was addressed by the following themes:

- Theme 1: The potential benefits of HHGE
- Theme 2: Future implications for natural immune responses

### *Theme 1: The potential benefits of HHGE*

The South African informed public endorsed the use of HHGE for its potential benefits, including *immunisation against serious infectious diseases*. In the discussions, participants emphasised not only the potential benefits for prospective individuals but also for society, given the high prevalence of serious infectious diseases in South Africa. Theme 1 was divided into two subthemes, which addressed (a) Benefits for the prospective individual; and (b) Benefits for society.

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[1366] Thaldar et al op cit note 92 at 6.

*(a) Benefits for the prospective individual*

At individual level, participants believed that HHGE would be advantageous in enhancing immunity against *serious infectious diseases*. Disease severity, akin to genetic health conditions discussed in SRQ1, was examined based on the *life-threatening* potential of the health condition. Furthermore, its possible impact on the *quality of life* of the prospective individual, despite the availability of medical treatment. In addition, consideration was also given to diseases that were 'not always preventable', such as HIV/AIDS (P7).

Infectious diseases, such as TB (P6) and HIV/AIDS, were considered severe due to their life-threatening nature. Life-threatening diseases emerged as a focal point of discussion among participants, warranting the use of genome editing for their very nature. TB was deemed sufficiently life-threatening or severe due to its capacity to target other vital organs (in addition to the lung), and its higher risk of mortality. Participant 10 accentuated the critical nature of life-threatening diseases like TB, suggesting that conditions with an increased mortality risk should be prioritised in potential HHGE applications. While several participants shared the opinion that TB could be effectively treated, some considered the development of drug-resistant strains when antibiotic courses were not completed, intensifying the risk of mortality. Similarly, despite arguments that ARV treatment could increase the life expectancy for HIV/AIDS, it was still interpreted as a chronic and potentially life-threatening condition by most participants. Interestingly, HHGE was viewed as a more promising avenue for potentially curing HIV/AIDS than current treatment methods (Participant 28). The severity of COVID-19 (P8) was explored minimally, on an individual level. Additionally, participants indicated that the common cold or flu (P9) was not adequately life-threatening or severe to warrant genome editing applications.

While medical treatment may be accessible, the participants still supported genome editing for diseases that were considered severe due to their impact on the quality of life. For some participants, these conditions may be treatable, but "the quality of life is not the same". To illustrate, several participants highlighted the prolonged periods of treatment and potential high costs involved, particularly when managing drug-resistant TB strains. HIV/AIDS was viewed even more critically in light of its effect on one's physical well-being or its capacity to weaken the immune system (Participant 11). As a result, it may amplify susceptibility to other infections and worsen the effects of present conditions, such as cancer (Participant 19). Another argument raised was the long-term nature of medical treatment, considering that HIV patients depend on medication for lifelong support. For some participants, this corresponded with a poor quality of life, as lifelong medication dependence may become burdensome and lead to psychological monotony and fatigue. Participant 17 also pointed to the issue of societal discrimination experienced by HIV individuals. In this respect, she feared that prospective parents may withhold the HIV-positive status of their children, which in turn, hinders their access to essential medical care. This does not only have implications for the child's physical health, but access to education and other social activities (Participant 2). Often rooted in the fear of being judged or receiving prejudicial treatment, participants provided that, some children may avoid school or any social interactions. Thus, the stigma attached to the condition could impact their quality of life by impeding access to healthcare, education and social activities.

In addition to these assertions, participants believed that HHGE should be permitted for serious infectious diseases, like HIV/AIDS, which are "not always preventable". The argument that certain diseases are "not always preventable" carried substantial weight in the study. Beyond perceptions of being life-threatening or impacting the quality of life, most participants supported the use of HHGE for HIV/AIDS, based on the mere reason that prevention is not always an option (in some instances). Acknowledging these various instances, participants highlighted that HIV transmissions could occur through sexual assault or rape; from mother to child; blood transfusions and accidental exposure to the virus when contact is made with infected blood. In referring to the South African context, Participant 27 stated that prevention of the virus may be implausible in rural areas, where there is a lack of adequate health care facilities.

The above observations validate an important claim in the literature– the level of acceptance of genome editing applications is often directly influenced by the severity of the disease.[1367] Similar to previous studies, such as the findings presented by Jedwab et al, participants were less concerned with the origin of the disease when evaluating disease severity.[1368] Thus, it did not matter if the condition was a genetic or an infectious disease– severity alone was a primary determinant of acceptance in the study. As a result, infectious diseases, such as TB and HIV/AIDS, were considered just as severe as the genetic health conditions discussed in SRQ1.

These results also reinforce the country-specific nature of participants' assessments of disease severity.[1369] In other countries, genome editing applications for certain infectious

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[1367] J Delhove et al op note 394 at 11.

[1368] Howell et al op cit note 369; Jedwab et al op cit note 356.

[1369] Thaldar et al op cit note 92 at 14.

diseases were flagged as immoral and a potential 'slippery slope' leading to 'unethical enhancements'.[1370] Conversely, the South African participants believed that TB and HIV/AIDS were sufficiently severe to justify HHGE applications. Thus, in addition to the previously stated factors (life-threatening nature, impact on quality of life and the challenge of prevention), the perceived severity of these diseases may also be attributable to the epidemic status of these infectious diseases in South Africa.[1371] This position was further explored in the next sub-theme.

*(b) Benefits for society*

At a societal level, the South African informed public expressed that HHGE could be utilised to prevent *serious infectious diseases* classified as epidemics in South Africa. This included TB, HIV/AIDS and, to a lesser extent, COVID-19, all of which have significant societal impacts. These diseases were often associated with high mortality rates, presenting a "greater threat to society" (Participant 25). The significance placed on genome editing for communicable diseases such as TB, HIV/AIDS and COVID-19 (albeit to a minor degree) divulges the public's focus on addressing health challenges and societal needs unique to South Africa. Thus, further affirming the "country-specific" nature of disease severity highlighted in the literature.[1372]

For instance, Participant 20 stressed that TB remains a major public health issue, owing to its severity and high mortality rates. Consistent with prior reports, TB stands as the principal cause of death in South Africa and a major contributor to global mortality.[1373] Furthermore, South Africa has the largest population of individuals living with HIV/AIDS in the world, which often ranks alongside TB in terms of mortality.[1374] As a result, participants emphasised the imperative to focus on diseases that had severe health outcomes and substantial mortality risks. While support for COVID-19 was comparatively lower, participants still acknowledge the profound loss of life caused by the pandemic, as extensively documented by the South African Medical Research Council.[1375] These findings may vary in countries where these diseases have lower prevalence rates.[1376] One participant in a Dutch study, notably, remarked

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[1370] Ibid.

[1371] Ibid at 15; Statistics South Africa op cit note 374; World Health Organization op cit note 374; Olivier & Luies op cit note 374 at 2, 1.

[1372] Thaldar et al op cit note 92 at 14.

[1373] Statistics South Africa op cit note 374; World Health Organization op cit note 374.

[1374] Olivier & Luies op cit note 374 at 2, 1.

[1375] SAMRC op cit note 374.

[1376] Thaldar et al op cit note 92 at 15.

that consideration would only be given to genome editing under circumstances where HIV prevalence was significantly higher, stating: 'If I would live in a country where HIV is more prevalent'.[1377] Thus, germline modifications to impart HIV resistance were deemed less essential in contexts where the risk of contracting the virus was lower.[1378]

Infectious diseases like TB and HIV/AIDS are renowned for their severe pressure on public healthcare systems, especially in under-resourced settings such as South Africa.[1379] Similar to most developing countries, South Africa grapples with a high burden of disease and resource limitations which have crippled healthcare systems, rendering them incapable of delivering high-quality care.[1380] In this context, the prevailing argument in the study was that genome editing for *serious infectious diseases* could have an overall positive impact on public healthcare by mitigating the burden of easily transmissible diseases. This would, in turn, ease the current strain on public healthcare resources and minimise the economic impact. As such, most participants opined that genome editing to confer immunity against *serious infectious diseases* would ultimately improve public health and well-being. Similarly, authors like Liang were optimistic that CRISPR technology could lead to major breakthroughs in addressing the severe health crises associated with infectious diseases.[1381]

Building on this, participants advanced that genome editing may be useful in reducing the burden of easily transmissible diseases like TB, HIV and COVID-19. This was especially relevant in South Africa, where such diseases were prevalent and spread rapidly. Similar to Liang's interpretation of non-communicable diseases,[1382] participants contended that while genetic health conditions (discussed in SRQ1) were more impactful at an individual level, they were not easily transmitted to others in society. As such, comparisons were made between serious genetic health conditions and infectious diseases, indicating that the former did not adversely affect societal well-being (Participant 25).

To illustrate, participants supported genome editing for TB owing to its highly contagious nature, presenting a major societal risk. As previous research has shown, TB is easily contracted through airborne particles when infected individuals cough or sneeze.[1383] TB

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[1377] Hendriks et al op cit note 361 at 8.
[1378] Ibid at 7.
[1379] Olivier & Luies op cit note 374 at 1; Maphumulo & Bhengu op cit note 1353 at 2.
[1380] Maphumulo & Bhengu ibid at 5.
[1381] C Liang 'New opportunities to meet the grand challenges in infectious diseases' (2020) 2 *Frontiers in Genome Editing* 1–3 at 2.
[1382] Ibid.
[1383] Thaldar at 15.

has also proven difficult to suppress in developing countries, such as South Africa, which lack the necessary health care infrastructure, exacerbating the spread of the disease.[1384] This includes overcrowded hospital conditions, excessive patient-to-staff ratios, insufficient isolation units, and poor infection control and prevention measures.[1385] Prior research has also revealed that overcrowded conditions play a crucial role in rising TB and HIV infections.[1386] This includes overpopulated rural settlements and insufficient access to public health care, which have intensified TB transmissions in South Africa.[1387] Similarly, Participant 18 referred to poor, densely populated communities, which, in his opinion, aggravate the spread of the disease. Public healthcare workers may also have an increased vulnerability to infections, due to their working environment (such as direct and frequent contact with TB carriers). Therefore, it was equally crucial to protect healthcare workers, who faced a significantly higher risk of contracting TB (Participant 25). In a similar vein, one participant highlighted the annual rise in HIV cases, regardless of individual choices (such as adopting preventive measures) or broader societal efforts, including awareness campaigns aimed at reducing infections. Moreover, despite significant declines in infection rates, HIV remains a major epidemic in South Africa, with new cases emerging each year. [1388] Additionally, given the absence of an HIV/AIDS vaccine, HHGE appeared a more promising solution in combating HIV (Participant 28). With COVID-19, participants contended that, although the vaccine may decrease the severity of infections, it may not fully inhibit transmissions.

Some academics have argued for the revolutionary potential of genome editing to combat infectious diseases and lessen the economic burden they place on global healthcare systems.[1389] In a similar breath, the South African participants envisioned that reducing the occurrence of serious infectious diseases could curtail long-term state expenditure, by easing the strain on public healthcare resources. The participants highlighted the impact of specific infectious diseases on the South African public healthcare system, particularly the challenges of meeting high demands for medical treatment, hospital care and specialised facilities. This was specifically explored when referring to the development of drug-resistant TB strains,

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[1384] Maphumulo & Bhengu op cit note 1353 at 5.

[1385] Ibid.

[1386] Olivier & Luies op cit note 374 at 7.

[1387] Ibid at 7, 4.

[1388] Thaldar et al op cit note 92 at 15; FL Johnson et al 'The effect of HIV programs in South Africa on national HIV incidence trends, 2000–2019' (2022) 90(2) *Journal of Acquired Immune Deficiency Syndromes* 115–123 at 121.

[1389] YM Hawsawi et al 'The state-of-the-art of gene editing and its application to viral infections and diseases including COVID-19' (2022) 12 *Frontiers in Cellular and Infection Microbiology* 1–17 at 5.

which, participants noted, lead to longer recovery periods and increased state expenditure. Statistics also confirm that drug-resistant TB cases continue to rise in South Africa, presenting a ‘major public threat’.[1390] For Participant 16, allowing clinical applications of HHGE for TB would not only help preserve state resources but allow for a redirected health focus towards emerging and future diseases. In a similar vein, Participant 9 viewed HIV prevention through HHGE as a more viable approach in reducing state expenditure, given the substantial costs associated with providing lifelong treatments to patients. These notable figures were detailed in a South African budget review, which disclosed an ongoing expenditure on HIV treatments, as South Africa continues to implement the largest treatment programme in the world.[1391]

The participants asserted that HHGE could also help reduce the economic impact of infectious diseases, in their capacity to disrupt daily life and undermine economic stability. For instance, a surge in TB cases lead to decreased workplace productivity, as employees take time off for medical treatment (Participant 19). Bloom and Cadarette emphasised the magnitude of such disruptions, particularly a decline in workforce productivity, highlighting the severe economic consequences of epidemics in general.[1392] This concern was especially salient in discussions on COVID-19, with several participants citing their personal experiences with its societal and economic repercussions, including the devastation that followed. These effects were often described as “catastrophic” (Participant 6). For example, disruptions in the employment sector increased the economic strain on state resources, where SRD grants had to be provided to unemployed individuals (Participant 1). Given that this study was conducted during the COVID-19 pandemic, these findings should be interpreted in the context of a rapidly evolving public health crisis. However, considering that COVID-19 is now less of an immediate public health emergency, these results may differ in current times.

### *Theme 2: Future implications for natural immune responses*

While the South African informed public acknowledged the immediate benefits of HHGE in conferring immunity against serious infectious diseases, they expressed concern about potential future risks if applied to less serious diseases. The participants believed that genome editing for immunity against less serious infectious diseases could be overly excessive, potentially leading to unintended or negative outcomes for prospective individuals, such as the

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[1390] N Ndlovu et al ‘A review of health, HIV and TB resource allocation and utilisation in South Africa’ (2019) 1 *South African Health Review* 201–213 at 202.

[1391] Ibid at 207, 202.

[1392] DE Bloom & D Cadarette ‘Infectious disease threats in the twenty-first century: strengthening the global response’ (2019) 10(549) *Front Immunol* 1–12.

loss of natural immunity. As such, (a) The potential loss of natural immunity, emerged as the only subtheme in Theme 2.

This potential loss of natural immunity is consistent with broader ethical debates in the literature, where the risk of inheriting an unintended or harmful genetic modification by future generations remains a critical ethical concern.[1393] Some scholars posit that the *heritability* nature of these genome editing applications could strongly influence how the associated risks are perceived and assessed by the public.[1394] This was evidenced in the study, where most participants feared that the unintended edit could be passed to prospective individuals.

The participants had notable reservations about the potential of HHGE to effectively impart resistance against less serious infectious diseases without tampering with natural immunity. While the idea of tampering with natural immunity is not widely explored in the literature, participants in prior studies have stated that genome editing for even diseases like TB or HIV could initiate a 'slippery slope'.[1395] One could only assume that these scholars associate said applications with potential negative outcomes. However, for the South African participants, genome editing for what they perceived as less serious diseases, like the flu or common cold, was deemed excessive or an "overkill" (Participant 28). In their opinion, it could have an adverse impact on natural immunity. In line with the 'dominant health-focused risk-benefit paradigm' in the study, participants feared that the potential risks of genome editing might outweigh its immediate benefits in this case.[1396] As with the literature, trade-offs may be necessary when considering genome editing applications for less severe health conditions.[1397] These risks may be considered acceptable when preventing severe conditions instead of what scholars term as 'trivial diseases'.[1398]

In the study, participants acknowledged the human body's innate capacity to combat infectious diseases through natural immunity, indicating a preference for the natural development of immune responses rather than gene modifications. Human beings, as participants noted, possess a remarkable ability to develop immunity through pre-exposure to pathogens and vaccinations. As Mueller and Rouse explain, when viruses enter the body, they come into contact with various innate defenses (innate immunity) and trigger adaptive immune

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[1393] Critchley et al op cit note 389 at 12.
[1394] Howell et al op cit note 369 at 3.
[1395] Thaldar et al op cit note 92 at 14.
[1396] Thaldar et al ibid at 13.
[1397] I van Dijke et al op cit note 393 at 467.
[1398] Ibid.

responses which are significant in eliminating the infection before it causes harm.[1399] Thus, for most participants, it was crucial to allow the body to be exposed to minor diseases in order to acquire this immunity. Participant 10, in particular, emphasised the importance of natural exposure to viruses or pathogens during one's childhood to strengthen the immune system. In this way, the body would be better equipped to fight off future infections (Participant 10). This is because the adaptive immune system utilises specialised receptors to recognise and react to particular antigens from external viruses or pathogens.[1400] Consequently, it can protect against future viral infections.[1401] As such, genome editing for the flu or common cold was considered unessential due to available vaccinations and the body's ability to naturally defend against the infection (Participant 2). Conversely, current research reveals that vaccines are only 40 to 60 percent effective in reducing the risk of the influenza virus, as it continues to replicate and new strains emerge.[1402] In this context, Rao, Appavu and Kethar believe that genome editing will eventually be more effective and easier "than ever" to inhibit these mutations.[1403] However, for the South African public, the severity of the condition did not warrant the use of the technology.

Beyond immunity, participants considered the wider evolutionary role of viruses in human development. For instance, Participant 22 asserted that the development of the human placenta can be traced back to interactions with a virus. This view is corroborated by research from Chuong, demonstrating the substantial contributions of ancient retroviruses in placental evolution.[1404] Van Blerkom also stressed the often overlooked but fundamental influence of infectious diseases in shaping human evolution.[1405] Participant 14 also emphasised the vital role of viruses in technological advancements like CRISPR-Cas9, indicating that the technology had evolved from bacteria interacting with viruses over time, a point supported by existing studies.[1406] These examples create the notion that interactions with certain viruses or pathogens, though unintended, can lead to developments that are ultimately advantageous. For

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[1399] SN Mueller & BT Rouse 'Immune responses to viruses' in RR Rich et al (eds) *Clinical Immunology: Principles and Practice* 3 ed (2008) 421–431 at 421, 423.

[1400] H Chi, M Pepper & PG Thomas 'Principles and Therapeutic Applications of Adaptive Immunity' (2024) 187(9) *Cell* 2052–2078 at 2052.

[1401] Ibid at 2060.

[1402] R Rao, RA Rohit & J Kethar 'Mutations In Influenza Viruses and Prevention Against These Viruses' (2022) 11(2) *Journal of Student Research* 1–11 at 5.

[1403] Ibid at 6.

[1404] EB Chuong 'The placenta goes viral: Retroviruses control gene expression in pregnancy' (2018) 16(10) *PLoS biology* 1–7 at 2.

[1405] LM van Blerkom 'Role of Viruses in Human Evolution' (2003) 122 (S37) *American Journal of Physical Anthropology: The Official Publication of the American Association of Physical Anthropologists* 14–46 at 15.

[1406] A Loureiro & GJ da Silva 'Crispr-cas: Converting a bacterial defence mechanism into a state-of-the-art genetic manipulation tool' (2019) 8(1) *Antibiotics* 1–25 at 2.

one participant, it was these evolutionary interactions that needed to be preserved. Accordingly, while viruses and pathogens are often viewed negatively, they may still be beneficial to individuals (Participant 14). Given this context, many participants were cautious about the idea of intervening in these natural processes, especially for minor health conditions. It was important not to accelerate evolution, especially in a way that would produce unintended consequences for future generations (Participant 14). Consequently, the participants feared that genome editing to confer immunity might disrupt natural pre-exposure to certain viruses, which is important for developing natural immunity. A few participants also extended this concern to COVID-19, though it was less pronounced.

Accordingly, in evaluating the potential risks, they raised the following questions. Firstly, would genetically engineered immunity hinder the development of natural immunity? If yes, would it make prospective individuals more prone to future infections or be as effective as natural immunity in fighting off diseases? Thus, the long-term effectiveness of genetically engineered immunity was a primary concern among South African participants. Conversely, this study was based on the assumption that genome editing would be both safe and effective prior to the approval of clinical applications, thus ensuring that it would not negatively impact natural immunity.

SRQ 3 was addressed by the following themes:

- Theme 5: The right to autonomy
- Theme 6: Going against human nature

### *Theme 5: The right to autonomy*

The South African informed public considered the ethical implications of genomic enhancements, including their potential to undermine the autonomy of future individuals. Theme 5 was divided into two subthemes which addressed: (a) The preservation of free will and personal identity; and (b) Informed consent and future consequences.

#### *(a) The preservation of free will and personal identity*

The concept of autonomy is central to the ethical evaluation of HHGE, as both the literature and participant responses demonstrate.[1407] According to participants, the defining quality of

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[1407] Almeida & Ranisch op cit note 378 at 9.

being human means the ability to exercise autonomy, a fundamental concept in medical ethics.[1408] This encompasses the freedom to make independent choices and to express *free will*. For them, the right to autonomy corresponded with the ability to make decisions based on one's own moral values and to determine your own life path. This perspective aligns with proceduralist accounts of autonomy, where it is understood as a higher-level capacity that enables individuals to evaluate their preferences and actions in light of their personal values and future plans.[1409]

As such, most participants asserted that allowing parents to genetically enhance and predetermine the characteristics of their children could inadvertently influence their future life decisions, restricting their autonomy in the future. Participant 19 emphasised this point when discussing genetic modifications to increase talents, like intelligence (P10). She expressed that, allowing parents to enhance the intelligence of their prospective children may be indirectly steering them towards a career path that they otherwise may not have selected with their natural talents. This resonates with Feinberg's notion of anticipatory autonomy rooted in liberal tradition and the 'right to an open future'.[1410] This right has been applied by some scholars in the context of genetic modifications, where it was significant that such procedures did not constrain the ability of prospective individuals to lead their lives based on their unique understanding of a good life.[1411] They accentuated the importance of preserving an individual's ability to make self-determined choices.[1412] In a similar vein, participants argued that decisions about sexual orientation should remain the prerogative of the prospective individual, who should be able to explore and express their sexuality without external interference. In this respect, participants feared that, if parents are permitted to make this decision for them before birth, it would subsequently remove from their right to make individual choices and express free will. A right which has been curtailed right before birth (Participant 4). According to Buchanan et al, genetic interventions should aim to provide offspring with 'all-purpose goods' or traits that broaden rather than narrow life opportunities.[1413] However, as the literature highlights, it is challenging to identify traits that universally expand life plans without simultaneously restricting certain possibilities.[1414]

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[1408] Ibid at 9.

[1409] Rueda op cit note 468 at 19.

[1410] Almeida & Ranisch op cit note 378 at 9.

[1411] Ibid.

[1412] Ibid.

[1413] Ibid.

[1414] Ibid.

The participants acknowledged the significant role of parental guidance and nurturing during a child's formative years but noted that this influence constitutes a relatively minor intrusion of free will, as compared to genome editing procedures (Participant 19). The importance of safeguarding a child's prospective right to autonomy was emphasised, with participants arguing that parental decisions, such as employing gene editing to determine sexual orientation– could compromise this right. Participant 1 characterised such actions as "overstepping" moral boundaries. Similar to the literature, the use of gene editing for such purposes was perceived as an extreme exercise of parental control, particularly due to the irreversible nature of the changes.[1415] Fukuyama, notably, likened germline modifications to giving your prospective child a 'genetic tattoo', such which the child or future generations can neither remove nor escape.[1416] In this respect, several participants questioned the scope of parental authority, asserting that it should not extend to decisions which irreversibly infringe upon the child's future right to autonomy.

For most participants, genetic enhancements lacked the necessary therapeutic motivation as would be present for critical health issues. As with the literature, participants made a clear distinction between therapeutic and non-therapeutic uses of HHGE.[1417] While there was broad support for using HHGE to prevent severe diseases, many participants believed that non-medical enhancements, such as improving intelligence or physical traits, should be left to the individual to decide. With disease prevention, most participants believed that the potential medical benefits would outweigh concerns about limiting the autonomy of prospective individuals. This resonates with arguments presented by Gyngell et al who suggest that, with the exception that the technology is proven safe and effective, genetic interventions to eliminate severe diseases are likely to enhance the autonomy of the prospective child.[1418] To illustrate, preventing severe or debilitating conditions could reduce the constraints imposed by these diseases, allowing them to lead better lives.[1419] For the participants, acting in the best interests of their children often meant that parents would consider taking extreme measures, such as genome editing, to impart a medical advantage. However, participants were unanimous in their belief that non-medical or cosmetic genomic edits should be left to individual choice. In this way, prospective children are able to make these decisions independently later in life.

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[1415] Ibid; Rueda op cit note 468 at 7.
[1416] Rueda ibid at 7.
[1417] Almeida & Ranisch op cit note 378 at 9.
[1418] Ibid.
[1419] Ibid.

In addition to the above, participants reflected on the broader implications of HHGE for identity formation and self-discovery. In their belief, the ability to exercise free will and make independent decisions is fundamental to developing an identity. This involves a process of self-discovery, where they argued that predetermining traits through genetic enhancement could inhibit a child's ability to explore their preferences and make life decisions integral to developing a true identity. In accordance with self-discovery, prospective children should be allowed to chase their ambitions and pursue their own life passions (Participant 11). This is consistent with Habermas's critique of genetic enhancement in *The Future of Human Nature*, where he argued that such interventions could undermine the future child's self-authorship conception as the primary author or architect of his/her own life.[1420] As a result, the development of personal identity is contingent on conditions which allow for 'self-authorship'.[1421] Habermas distinguished between what is 'grown' and what is 'made', suggesting that while the former embodies natural development, the latter represents a technically engineered existence.[1422] As a result, these genetic enhancements could disrupt an individual's perception of being the autonomous creator of his/her own life, instead creating the belief that their identity has been pre-designed by others.[1423]

In a similar vein, some participants perceived genetic enhancements as a way of "programming" children to conform to parental ideals. To illustrate, Participant 2 opined that genetic manipulations to enhance intelligence or athleticism could be effected to enhance the self-image of prospective parents or for their own gain. Parents may use genome editing to project their own interests or societal expectations over their children rather than their authentic inclinations, subsequently undermining their future autonomy (Participant 2). Such manipulations, as Habermas noted, could impose 'irreversible intentions of a third party', limiting the child's ethical freedom and individuality.[1424] As such, one participant emphasised the value of individual choice, indicating that parents should instead support their children in cultivating their own identities.

Some participants also warned against the risk of "alienation" of the prospective child, precisely when parents choose characteristics (such as traits or physical features) dissimilar to their own. They expressed concern that altering certain genetic traits or characteristics could

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[1420] Rueda op cit note 468 at 9.
[1421] Ibid.
[1422] Ibid.
[1423] Ibid.
[1424] Ibid.

sever the biological connection between prospective children and their progenitors, which many considered essential for personal identity. As outlined in the UDHGHR, the human genome is described as the shared and unique 'heritage of humanity', embodying both the dignity and diversity of all individuals.[1425] Thus, the participants' concern of alienation reflects a broader critique of germline manipulation, such as its capacity to threaten this collective heritage.[1426] According to Participant 14, the connection between parents and their children provided a sense of pride, ancestral history, and an understanding of family heritage, which are vital to one's identity. Thus, while it can still be argued that the genetic link in terms of overall inheritance remains intact, participants believed such modifications could create a perceived disconnect, as the prospective child may possess characteristics or traits that do not align with their family lineage or heritage.

*(b) Informed consent and future consequences*

An additional concern highlighted by participants is the inability of prospective individuals to provide informed consent to a procedure that could profoundly impact their future autonomy. Participant 27 emphasised that autonomy fundamentally entails the capacity to make independent decisions, which should not be imposed by others. In the context of genome editing, this principle is echoed by Almeida and Ranisch, who assert that every individual has the right to make decisions about their own body, emphasising the significance of protecting one's physical integrity.[1427]

The right to autonomy and self-determination are recognised as fundamental rights in many contemporary societies, extending to all individuals, including children.[1428] However, while such rights are arguably applied to living persons capable of legal subjectivity, the participants felt that allowing parents to make these decisions on behalf of a future life that they would not personally live, infringes on these rights. This concern aligns with Smolenski' argument that heritable genome interventions pose a unique ethical challenge, as future generations are unable to consent to modifications that may significantly shape their lives or affect their future autonomy.[1429] As a result, there is an inherent uncertainty as to whether the prospective child would accept or reject the genetic modifications imposed upon them.

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[1425] Almeida & Ranisch op cit note 378 at 8.
[1426] Ibid.
[1427] Ibid at 9.
[1428] Ibid.
[1429] Ibid.

Many participants expressed concern that parental decisions to alter certain physical attributes or traits might result in modifications that the child may later disapprove of. This was particularly critical, given the irreversible nature of the modification. Thus, it was significant that prospective children be granted the opportunity to consent to a procedure of this magnitude. Some participants also feared that the genetically induced change would not align with the prospective child's future interests or preferences. There is a real possibility that the child might have preferred a different modification or no modification at all, if given the choice (Participant 19). In modern healthcare systems, informed consent is a cornerstone of medical ethics.[1430] Beauchamp and Childress emphasise that informed consent enables individuals to make autonomous decisions about medical interventions, based on a comprehensive understanding of the potential benefits and risks.[1431] By contrast, heritable genetic modifications deny future generations this right, transferring the decision-making power entirely to parents or the present generation.[1432] In this respect, several participants highlighted the potential for significant societal, cultural or legal repercussions stemming from certain genetic enhancements. To illustrate, Participant 22 raised concerns about the consequences of modifying a child's sexual orientation, particularly in communities or countries where homosexual identities are stigmatised, criminalised or even killed. In light of these concerns, the participants collectively agreed on the importance of ensuring that prospective children retain the ability to make decisions independently and with full awareness of the potential repercussions of the genetic modification. They emphasised that informed consent is not only a fundamental value in medical ethics but also an essential safeguard for respecting the autonomy of prospective individuals.

*Theme 6: Going against human nature*

The South African informed public posited that HHGE for genetic enhancements constitutes an intervention in natural processes with the potential to fundamentally alter human nature, leading to far-reaching consequences for both individuals and society. Concerns were raised about the risk of a slippery slope towards ethically contentious practices, such as the creation of designer babies. Additionally, broader societal implications were highlighted, including the disruption of the essential balance between nature and nurture and the potential erosion of genetic diversity, which is significant for societal well-being. Theme 6 was divided into three

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[1430] Ibid.
[1431] Ibid.
[1432] Ibid.

subthemes, which addressed: (a) Heading down a slippery slope; (b) Nature vs Nurture; and (c) The loss of genetic diversity.

### *(a) Heading down a slippery slope*

A pressing moral and ethical issue voiced by the participants is the risk that certain genomic modifications could lead society down a *slippery slope* towards increasingly contentious applications. This argument is arguably one of the more compelling objections against HHGE applications in general.[1433] Many scholars who share this perspective have opposed therapeutic genetic modifications on the basis that it could pave the way for ethically problematic applications, such as genetic enhancements.[1434] In a similar vein, the South African participants believed that allowing genome editing applications for enhancements could initiate a slippery slope towards more unacceptable applications, such as *designer babies*.

The participants raised concerns that initial genetic interventions to improve intelligence or certain talents could eventually give rise to more unethical modifications, enabling parents to design or customise their children. For some critics, genetic enhancements could progress to a point where they resemble a commercial market, with 'parent-consumers' selecting their children's traits.[1435] In this context, the participants raised an important question, namely, *where do you draw the line?* If genetic enhancements are permitted, it may be challenging to establish clear ethical boundaries between what is ethically permissible or not, as would be the case with therapeutic genome applications. Thus, while the participants acknowledged that the technology may be valuable in addressing severe health issues, they were apprehensive about the idea of selecting or 'handpicking' specific traits for future children (Participant 21). They raised alarms that the concept of designer babies could become more common as genetic enhancements become accessible to the general public.

An intriguing observation in the study was that several participants displayed a willingness to explore genetic enhancements when it could impart a medical benefit. Similarly, as some studies have revealed, certain genetic enhancements may be met with approval when there is a compelling rationale or meaningful purpose behind them.[1436] As such, a subset of participants supported genetic enhancements to increase the intelligence of children with

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[1433] D Resnik 'Debunking the slippery slope argument against human germ-line gene therapy' (1994) 19(1) *The Journal of medicine and philosophy* 23–40 at 23.

[1434] National Academies of Sciences, Engineering, and Medicine op cit note 28 at 98.

[1435] TR Melillo 'Gene editing and the rise of designer babies' (2017) 50(3) *Vanderbilt Journal of Transnational Law* 757–790 at 760.

[1436] Thaldar et al op cit note 92 at 4.

possible below-average IQ levels. In this context, genome editing was perceived as a form of 'corrective therapy' for prospective children with learning disabilities. Additionally, some participants emphasised that increasing a child's IQ to normal levels would also subsequently improve his/her quality of life, becoming even more advantageous. Thus, consistent with the literature, the intended purpose of gene editing was crucial,[1437] suggesting that genetic enhancements for intelligence may be acceptable if they could confer a medical benefit. However, returning to the core argument, participants raised concern that it may be difficult to define the ethical limits or boundaries of these applications, precisely when perceptions of what is considered average intelligence evolve over time. This may blur the line between what is considered normal (average) or super intelligence, resulting in genome editing applications which potentially exceed moral and ethical limits. On the contrary, the line may be more clear with therapeutic genetic interventions, where there is a clear and positive impact on the life of the prospective individual (Participant 9).

For the participants, it was essential to restrict the use of HHGE to health-related conditions, in order to prevent a potential shift towards unethical enhancements. Accordingly, they feared that genome editing might advance to a point where parents could design or customise their children based on personal preferences or societal trends, a concern also highlighted by Youvan.[1438] Participant 7 also cautioned that trend-driven genetic modifications could result in increasingly bizarre or extreme modifications, reinforcing the broader argument that such applications may overstep moral limits and should be prohibited.

An additional concern shared by participants was that allowing parents to design their children could lead to the *commodification of human life*, a common argument against the concept of designer babies.[1439] As such, many feared that prospective children would be treated as customisable objects of parental desire rather than individuals with inherent human dignity. Scudder expands on this belief by likening the implementation of HHGE for designer babies to a 'market-like enterprise, where one can buy their child'.[1440] For Participant 21, this could diminish the fundamental value of being an "organic human being," reducing children to objects that are tailored to parental preferences. It could also result in shifting societal attitudes towards prospective children, where they are viewed as personal creations rather than human-

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[1437] T Sawai et al op cit note 367 at 11.

[1438] Youvan op cit note 413 at 5.

[1439] PL Lau 'Evolved Eugenics and Reinforcement of "Othering": Renewed Ethico-Legal Perspectives of Genome Editing in Reproduction'(2023) 12(3) *BioTech* 1–14 at 5.

[1440] A Scudder 'The Ethicality of Gene Alteration in Human Embryos' (published research paper, Augustana College, Rock Island Illinois, 2024) at 5.

beings. Participant 6 compared the situation to treating a child as a "pet" rather than a person, emphasising the risk of dehumanisation. Thus, genetic customisation could foster a sense of ownership rather than guardianship, altering the traditional parent-child relationship. The aforementioned opinions align with the beliefs of Biggs, who fears that the possible commodification of children, by way of HHGE, will alter the values of parenthood by shifting the focus from unequivocal love and acceptance to an unhealthy model of parental self-gratification[1441]

Several participants also linked the concept of genomic enhancements to the act of "playing God", in which parents would assume a divine role (Participant 9). Mattielo raised similar concerns, likening the human genome to 'the language with which God created life' and 'an autobiography of the human species'. [1442] She further cautions that the use of HHGE may provoke religious objections, particularly with regard to its ethical implications.[1443] Additionally, some participants feared that permitting genetic enhancements could resurge dangerous eugenic ideologies. Some scholars have questioned whether the use of HHGE for non-medical purposes edges toward the realm of eugenics.[1444] Kromer reinforces these worries, asserting that HHGE could represent a significant threat to humanity through the potential revival of eugenic practices.[1445] In a similar context, Participant 26 warned that allowing genetic selection for non-medical traits, such as skin tone or intelligence, could usher in a modern form of eugenics. Furthermore, the notion of creating the "most optimised" (Participant 21) or "ideal" human being (Participant 9) could mirror past efforts to engineer a so-called superior race.

*(b) Nature vs Nurture*

The South African informed public have unwittingly found themselves ensnared in the age-old nature vs nurture controversy,[1446] which continues to captivate and complicate our understanding of human development. As with previous research, the participants emphasised the complex relationship between genes and the environment in shaping an individual's

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[1441] H Biggs 'Designer babies: where should we draw the line?' (2004) 30(6) *Journal of Medical Ethics* 1–1 at 1.
[1442] E Mattiello '"Designer babies" and "Playing God": Metaphor, Genome Editing, and Bioethics in Popular Science Texts' (2019) *6*(1) *Lingue Culture Mediazioni* 65–88 at 68.
[1443] Ibid at 69.
[1444] A Schmerge 'Designer Babies: A Paired Analysis of the Technological Advances and Ethical Implications of Genetic Selection' (published Honors thesis, DePauw University, 2018) at 50.
[1445] A Kromer 'Designer Babies: The Ethical and Societal Effects' (published research paper, College of Saint Benedict/Saint John's University, 2018) at 13.
[1446] Reese op cit note 440 at 3.

personality or behavioural traits.[1447] Contrary to some scholars, they were firmly convinced that both nature and nurture were equally integral in shaping genes.[1448] Modern research has also shifted away from this binary argument, instead appreciating the unique and substantial contributions of both nature and nurture in individual personality differences.[1449]

In the study, participants challenged the assumption that genetic factors alone were responsible for the traits that manifested in individuals. Similar to participants in a Dutch public opinion study, the South African participants argued that environmental factors were equally as important in influencing behavioural or personality traits.[1450] This contradicts Galton's belief that one's cognitive abilities (like intelligence) were predominantly attributable to genetic factors.[1451]

The participants did not establish a strict dichotomy between genes and the environment but instead highlighted their intrinsic overlap in shaping traits. Participant 6 acknowledged that while individuals may have a genetic predisposition for certain behavioural traits, their development and expression also depend on their surroundings or living environment. For Participant 26, these were external or outside factors which also impacted genes. This stance may be correct, considering previous research which revealed that novel experiences stimulate a new form of brain development.[1452] Furthermore, exposure to certain environmental factors can induce permanent genetic alterations and have lasting effects on gene activity.[1453]

Accordingly, Participant 1 expressed that genomic enhancements may be "futile" as they cannot guarantee a particular behavioural trait or entirely nullify environmental influences. As such, while genetic predisposition plays a major role in determining the expression of genes, many participants were concerned that environmental factors may ultimately enhance or even override genetic influences. To illustrate, Participant 2 asserted that even if a child were genetically less aggressive, exposure to an aggressive environment could still lead to aggressive tendencies. Thus, certain traits may be nurtured in an environment where they are the norm or beneficial. Moreover, one participant indicated that specific personality disorders, such as BPD, often require environmental "triggers", like trauma, to manifest fully.

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[1447] Ibid at 7–8.
[1448] Ibid at 4, 6.
[1449] Ibid at 7.
[1450] Van Dijke et al op cit note 393 at 470.
[1451] Badcock op cit note 441 at 340.
[1452] Reese op cit note 440 at 10.
[1453] Ibid at 10.

The participants' responses suggest that although genetic enhancements may offer a degree of influence over behavioural traits, they cannot account for the unpredictable role of environmental factors. Consequently, it can be argued that, while recognising the interplay between nature and nurture, the South African participants viewed environmental factors as having a more substantial influence on gene expression. However, determining the full extent of this perceived influence falls beyond the scope of the study and warrants exploration in future research.

Genome editing may not entirely neutralise the effects of environmental factors; however, this was not interpreted negatively by the participants. In some instances, they asserted that a balance between nature and nurture was essential to uncover the full potential of certain talents or traits. In this regard, they emphasised that even with an inherent or genetically modified advantage in intelligence, a child would still require hard work and a conducive learning environment to truly benefit from this genetic predisposition. For similar reasons, Resnik and Vorhaus have claimed that the idea of 'strong genetic determinism' is flawed.[1454] They explained that a genetically enhanced person cannot be a passive subject, but is still required to dedicate a significant amount of time and effort to achieve success.[1455]

On the other hand, some participants leaned towards a strong genetic determinism perspective,[1456] asserting that certain genomic enhancements could undermine the significance of key environmental factors. They maintained that genetically enhancing a prospective child's intelligence may diminish the value of, and incentive for hard work. In their view, cognitive abilities such as intelligence were not solely appreciated for their innate existence but for the hard work and effort which contribute to their development (Participant 8). According to the participants, the concept of hard work was integral to personal fulfilment, intellectual growth and societal recognition. Firstly, accomplishments driven solely by genetic factors (such as increased intelligence) cannot equate to the level of personal achievement and fulfilment that is derived from attaining it through hard work (Participant 17). Secondly, the lessons learned through rigorous tasks or life struggles were invaluable for self-growth and intellectual development, potentially leading to innovative ideas or novel concepts– critical traits for new discoveries (Participant 10). Lastly, the participants noted that success earned through hard work commands a greater level of respect in society, where such individuals are valued

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[1454] Resnik & Vorhaus op cit note 414 at 4, 8, 9.
[1455] Ibid at 8–9.
[1456] Ibid at 4.

differently. As a result, some participants expressed concern that success would no longer be determined by hard work and personal effort but rather by genetic predisposition. This apprehension aligns with the authenticity critique in the literature, which posits that if an individual's abilities or talents result from genetic modification, they may be perceived as a product of the intervention rather than personal development.[1457] However, reinforcing Resnik and Vorhaus's argument, genetic factors cannot be entirely disentangled from environmental influences.[1458] Therefore, a level of hard work and effort would still be required, even for someone with genetically engineered intelligence.[1459]

Given the concerns voiced by participants, the prevailing argument was that "the great nurturing" was always better (Participant 10). They believed that certain talents or behavioural traits could be cultivated naturally within a supportive environment without the need for extreme measures, such as genome editing. Participant 8 highlighted the role of certain environmental factors, such as good parenting and upbringing, asserting that certain traits could be naturally conferred rather than genetically engineered. For Participant 3, prospective children could be educated and led on how to be less aggressive rather than exploring genetic interventions. Accordingly, participants indicated a preference for the natural route in personality development, where both genetic predispositions and environmental factors play integral roles.

### *(c) The loss of genetic diversity*

The participants contended that permitting HHGE for enhancements could have profound societal effects, particularly concerning the *loss of genetic diversity*. They had strong beliefs that genetic enhancements could undermine genetic variation, which is significant for societal well-being. Participant 22, reinforcing this collective stance, emphasised that the preservation of diversity was a key reason for opposing genomic enhancements altogether.

The potential reduction of genetic diversity is a well-founded unintended consequence acknowledged by scientists, scholars, and the broader public,[1460] given that the technology remains in its infant years and the full risks are not yet fully comprehended.[1461] Scholars,

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[1457] Ibid at 8.

[1458] Ibid at 8, 9.

[1459] Ibid.

[1460] Youvan op cit note 413 at 8; COGEM/Health Council of the Netherlands op cit note 413; KA Riggan, RR Sharp & M Allyse 'Where will we draw the line? Public opinions of human gene editing' (2019) 29(12) *Qualitative Health Research* 1–13 at 6; Alonso op cit note 413 at 41.

[1461] Youvan ibid at 8.

including Rifkin, have raised alarms that genetic modifications could produce a form of homogeneity, resulting in the loss of diversity.[1462] Significantly, this was an overarching concern observed among the South African participants. They delineated various ways in which certain genomic enhancements could disrupt and reduce genetic diversity, with the foremost concern being that widespread genetic modifications could lead to a homogeneous society. For example, prospective parents may genetically enhance their children to reflect fashionable or societal trends, resulting in similar future individuals. For some scholars, this paints a dystopian picture of a future where genetic technologies give rise to populations that may resemble 'quasi-clones' with little phenotypic variation and one of uniformity.[1463] Participant 18 also warned against potential adverse outcomes, such as creating a "zombie society". In his opinion, it could lead to a world where distinct characteristics and *individuality* are lost, as everyone shares the same physical characteristics and behavioural traits. Researchers have argued that genetic enhancements could alter societal values, shifting priorities toward 'genetic perfection'.[1464] This could contribute to a homogenised society where individuality is diminished, diversity is compromised and genetic attributes are subject to curation and control.[1465] Consequently, some participants were apprehensive that genetic enhancements, likely to create homogeneity, could erode the intrinsic and fundamental value of being *unique*.

The notion of individuality or uniqueness is grounded in the differences observed in people's physical attributes, personality traits and talents (Participant 1). According to participants, each person is designed to be different, characterised by their own unique set of virtues and weaknesses. This diversity was an integral part of the "human experience" that ought to be protected (Participant 9). As scholars like Youvan have argued, restricting genetic variation could remove from the 'richness' and creativity of this experience.[1466] On the contrary, another notable argument is that genetic composition may not play as significant a role in shaping personal identity as some critics of genetic enhancements suggest.[1467] Rightly so, genetic uniqueness is often insignificant to people who derive their individuality from

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[1462] Kirby op cit note 416 at 5.
[1463] Alonso op cit note 413 at 41.
[1464] Youvan op cit note 413 at 12.
[1465] Ibid.
[1466] Ibid at 8.
[1467] Resnik & Vorhaus op cit note 414 at 9.

environmental and personal experiences.[1468] Thus, one's uniqueness cannot be attributable to genetic factors alone.

Several participants also emphasised the fulfilling and enriching aspects of diversity, which enhanced life experiences. Participant 15 highlighted that engaging with individuals from various backgrounds and with different characteristics added joy and depth to life, making it less mundane. Similarly, Participant 4 expressed agreement with the notion that a world filled with homogeneity, where everyone is equally intelligent, would be dull and lacking in excitement. This sentiment was echoed by others who felt that the richness of human interaction originates from the differences that people bring to society. Participant 19 elaborated further, noting the aesthetic value of diversity. She explained how the uniqueness of individuals, whether it be their hair texture or skin colour, can be striking and beautiful, reflecting the diverse world that we live in. One participant extended this idea, linking physical attributes to cultural identity or heritage. Thus, similar to the assertions by Resnik and Vorhaus', she expressed that gene editing applications aimed at altering aesthetic traits, such as skin colour, might lead to a reduction in not only genetic but cultural diversity.[1469]

A secondary concern forwarded by the South African participants was the potential for genetic enhancements to produce *societal imbalance* through the loss of diversity. Thus, beyond its aesthetic appeal, the participants believed that diversity served multiple functions in society itself. This notion was shared by participants in another public opinion study, who indicated that genetic uniformity and the potential loss of social diversity could negatively impact society's 'collective functioning'. [1470] Analogous to our research, these participants feared that such genetic interventions could remove individuals with unique contributions to society.[1471] As the South African participants highlighted, individuals with varying levels of intelligence contribute to society in distinct ways and occupy roles that align with their unique capabilities or skills (Participant 2). Participant 25 expanded this concept by discussing the complementary roles of introverts and extroverts in society. He emphasised that while introverts may excel in critical thinking, extroverts contribute the social skills that the former lack, thus both personality types are crucial for societal cohesion and success. In this respect, the participants agreed that a well-functioning society depends on a balance between various skills and qualities that individuals possess, each contributing uniquely to its development. As

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[1468] Ibid.
[1469] Ibid at 5.
[1470] Riggan, Sharp & Allyse op cit note 1460 at 6.
[1471] Ibid.

a result, enhancing intelligence or other traits through genome editing could disrupt said balance.

According to the participants, permitting genetic enhancements could reduce the prevalence of other valuable attributes or talents necessary for societal functioning. For example, genetic enhancements to increase intelligence could result in an excess amount of individuals in a similar career path, limiting the diversity of other creative and artistic fields (Participant 16). In his view, prospective parents may be inclined to choose genetic enhancements that are consistent with what they consider prestigious fields, including medicine or science, at the expense of other equally valuable fields like music, which may suffer from a reduced interest by prospective children (Participant 16). According to one participant, it is these fields that add to the quality and vibrancy of human life. On the contrary, it has been argued by Powell that society lacks a unified concept of what is universally 'good', meaning that genetic choices will likely vary according to individual parental preferences.[1472] In line with Mill's idea of 'experiments in living', just as parents shape their children's characteristics and skills through education, genome editing allows for this potential in reproduction.[1473] This analogy highlights the possibility of diversity in genetic selection, as different families prioritise differing traits or education.[1474] Conversely, critics like Gyngell contend that a level of uniformity may still be expected for some desirable traits.[1475]

There is a growing fear among bioethicists that certain traits perceived as undesirable by society could be eradicated from the entire human population.[1476] For the participants, this could result in the loss of other valuable or impactful traits. In this context, they highlighted the potential *genetic trade-offs* that may occur when certain behavioural traits are genetically enhanced (improved or eliminated). For example, some participants feared that modifying or removing genetic traits like aggressiveness might inadvertently remove competitiveness, a characteristic often linked to success in fields like sports and academia. Participant 22, for instance, emphasised that competitiveness plays a significant role in driving individuals to push their limits or excel, stating that without this drive, even academically inclined individuals may lack the motivation to succeed or surpass others in society. Consequently, genetic

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[1472] Alonso op cit note 413 at 41.
[1473] Ibid.
[1474] Ibid.
[1475] Ibid.
[1476] Kirby op cit note 416 at 5.

enhancements in this respect could result in fewer competitive individuals or those motivated to succeed in different fields.

Accordingly, genetic modifications, while promising in enhancing certain traits, carry inherent risks due to the complexity of the human genome and the concept that genes do not function in isolation.[1477] In a similar vein, participants indicated that increasing one's level of cooperativeness through genome editing could, in turn, reduce one's disagreeableness or ability to be assertive. Consistent with the literature, certain positive attributes may emanate from personality or behavioural traits that are sometimes viewed negatively,[1478] including disagreeableness. For some participants, disagreeableness was associated with assertiveness, which they considered essential for personal growth and societal progress, including pursuing unique life paths (being individualistic) or being a catalyst for societal innovation. While these downstream effects of HHGE are a long-term possibility, these arguments assume that genetic modifications will follow a singular societal trend. Furthermore, they overlook the potential for regulated, ethical enhancements that could safeguard a wide variety of traits.

Interestingly, several participants also emphasised the role of diversity in how societies respond to health crises like the COVID-19 pandemic. They indicated that homogeneous populations faced increased mortality rates compared to those which reflected higher levels of diversity. These findings give credence to the assertions made by some scholars regarding the 'long-term evolutionary' effects of genome editing.[1479] Similar to previous research,[1480] participants shared the opinion that genetic diversity is crucial for the adaptability and survival of populations against certain infectious diseases, which could eliminate individuals of a "specific phenotype" (Participant 3). In this respect, Youvan contended that a lack of genetic variation within a population may increase its susceptibility to diseases.[1481] As such, the role of diversity is significant in various aspects of human life, serving a wider function in society, as noted by the South African participants.

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[1477] Youvan op cit note 413 at 8.
[1478] Gyngell op cit note 424 at 278.
[1479] Youvan op cit note 413 at 8.
[1480] Ibid at 15.
[1481] Ibid at 8.

## III CONCLUSION

This study aimed to integrate public perspectives with scientific innovations, particularly CRISPR-Cas9, to inform the future regulation of HHGE in South Africa. In light of the ethical and social dilemmas associated with HHGE, this research sought to engage the public in defining the parameters of acceptable use of this technology, thereby providing valuable insights for policymakers in shaping future HHGE policies. Through extensive deliberations with an informed public over three evenings and a thematic analysis of participants' responses, the study sought to address the central research question: What is the perspective of the informed South African public on HHGE? In order to answer this question, the study examined the perspectives of the informed public on the acceptability of HHGE across three primary applications: (1) prevention of serious heritable genetic conditions, (2) immunity enhancement against infectious diseases, and (3) genetic enhancements. In addressing the central research question, the following subsidiary research questions were developed:

- SRQ 1: What is the informed South African public perspective on the use of HHGE to prevent genetic health conditions?
- SRQ 2 What is the informed South African public perspective on the use of HHGE to enhance immunity against infectious diseases?
- SRQ 3: What is the informed South African public perspective on the use of HHGE to edit for genetic enhancements?

Additionally, the study aimed to understand:

SRQ 4: Why did the informed South African public change their opinions during the study?

This section provides a summary of the key findings from the research, answers the research questions in relation to the emerging themes and discusses the limitations of the study. It is divided into the following subsections:

(a) Summary of key findings; (b) Answering the Research Questions; and (c) Limitations of the study.

### *(a) Summary of key findings*

#### *(i) Public Support for therapeutic HHGE applications*

- The informed South African public strongly supports HHGE for the prevention of *severe* genetic health conditions and infectious diseases that are *life-threatening* or could significantly impact the *quality of life* of the prospective child. This includes the prevention of serious infectious diseases, such as TB, HIV/AIDS and COVID-19, which are prevalent and have a severe impact on South African public healthcare resources and the economy (context-specific attitudes).
- There was conditional support for genetic health conditions that had varying levels of severity and were potentially life-threatening (such as asthma); or conditions that were life-threatening due to environmental or social factors in South Africa (such as albinism).
- There were lower levels of support for less severe infectious diseases, like the flu or a common cold, due to the potential loss of natural immunity.

#### (ii) *Equitable access was a fundamental value*

- The informed South African public supported HHGE applications for serious genetic health conditions, provided that the government enables equitable access to the technology for everyone.
- Financial barriers were a major concern, with participants fearing that HHGE could exacerbate socio-economic inequalities, benefiting only the wealthy.
- Participants called for active government intervention, including subsidised access for low-income individuals and prioritisation of severe genetic health conditions.
- Some participants expressed scepticism toward the government's capacity to enable equitable access, given existing resource constraints in South Africa's healthcare system. They suggested that the private healthcare sector collaborate to enable equitable access for everyone.

#### *(iii) Potential for discrimination*

- The informed South African public supported HHGE for certain genetic health conditions (such as disabilities), despite concerns that it could aggravate societal discrimination.
- Some participants raised fears about the impact of HHGE on societal acceptance towards disabilities, suggesting a negative impact.

- The majority of the participants rejected the idea that HHGE inherently devalues or discriminates against disabilities or people living with them.
- The purpose of HHGE was not to heighten discrimination, but to improve the health and well-being of society (quality of life).
- Discrimination was a separate societal issue and should not be conflated with the purpose of HHGE.

*(iv) Strong opposition for genetic enhancements*

- The informed South African public displayed strong opposition towards genetic enhancements (e.g., intelligence, physical traits) due to their potential risks to the individual (violating future autonomy) and society (going against human nature).
- These risks included undermining the autonomy of prospective children by limiting their ability to exercise free will, develop an authentic sense of identity and provide informed consent to an irreversible modification of their genome.
- The participants also warned against a 'slippery slope' towards more controversial applications, where it may be difficult to draw the line between HHGE applications that are ethically permissible or not; and the potential commodification of human life.
- There were also fears that widespread HHGE applications for genetic enhancements could reduce genetic diversity, leading to homogenised populations. This could result in the loss of valuable talents and traits that were vital for the well-being and functioning of society.
- The participants emphasised that both nature (genes) and nurture (environmental factors) contribute to shaping personality and behavioural traits, and HHGE could disrupt this balance. They believed that desirable traits could be nurtured in a supportive environment without the need for HHGE.

*(v) Inconclusive evidence for changes in public opinion*

- There were inconsistencies between the quantitative (survey results) and qualitative data (transcripts), making it challenging to trace the reasoning for opinion changes in the study.
- The potential justifications for opinion changes were unclear, limiting the ability to determine whether the changes were influenced by the deliberations or external factors.
- Opinion shifts were not always reflected in the survey data despite participants making verbal expressions of opinion change during the deliberative discussions, further complicating the analysis.

### *(b) Answering the Research Questions*

*SRQ 1: What is the informed South African public perspective on the use of HHGE to prevent genetic health conditions?*

This research question was addressed by Theme 1 (the potential benefits of HHGE), Theme 3 (equitable access to HHGE for everyone) and Theme 4 (HHGE and discrimination in society).

*Theme 1: The potential benefits of HHGE*

The informed South African public believed that HHGE for serious genetic health conditions should be permitted due to its potential benefits for the prospective individual.

- This includes the prevention of health conditions that were adequately severe. The severity of the health condition was significant in their support for HHGE applications.
- Disease severity was examined against its potential to be life-threatening or impact the quality of life of prospective children.
- The participants believed that HHGE could be beneficial for genetic health conditions that are either intrinsically life-threatening (like sickle cell anaemia, muscular dystrophy, or Alzheimer's) or have the potential to become life-threatening (such as asthma). Additionally, HHGE could be used to prevent health conditions that are life-threatening due to environmental or social factors unique to South Africa, such as albinism. This aligns with Thaldar et al's claim that 'country-specific' factors may be relevant when assessing the public's perceptions of disease severity.[1482]
- HHGE may also be beneficial for genetic health conditions that have a profound impact on the quality of life or the ability of the prospective child to lead a normal, fulfilling life. This included conditions that affect one's physical and mental well-being (such as sickle cell anaemia), as well as cognitive and intellectual capacity. The participants also considered the potential impact of certain health conditions (such as disabilities and Down's syndrome) on the social and financial well-being of the prospective child. This included the ability to be independent, secure employment or have a traditional family life. Moreover, the financial burden of managing chronic conditions, such as the costs of medical treatment or the need for specialised education (for disabilities and Down's syndrome).

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[1482] Thaldar et al op cit note 92 at 14.

*Theme 3: Equitable access to HHGE for everyone*

The informed South African public supported HHGE applications on the condition that the technology is made equally accessible to everyone.

- They believed that potential financial barriers could prevent access to the technology for certain societal groups, increasing the existing socio-economic divide between the rich and poor. They believed that the South African government should actively intervene in addressing the issue of accessibility.
- Equitable access to technology for everyone should not be a precondition to the use of HHGE; however, the government should take a proactive role in ensuring that it becomes accessible to everyone over time.
- The participants proposed two strategies that the government could implement to enable equitable access. In their first strategy, they suggested the prioritisation of severe health conditions first, with the expectation that over time, as resources allow, the technology would become accessible for all health conditions. In their second strategy, the participants proposed a targeted approach, in which the government should provide financial support exclusively to low-income or marginalised societal groups.
- The participants acknowledged the significance of governmental intervention, but raised concerns about its ability to effectively implement strategies for equitable access, due to existing resource constraints and socio-economic challenges in South Africa. In this regard, they supported a collaborative approach, involving both the public and private sectors to bridge resource gaps and enable equitable access to everyone.

*Theme 4: HHGE and discrimination in society*

The informed South African public supported the use of HHGE, notwithstanding concerns that some clinical applications could exacerbate societal discrimination.

- Some participants raised concerns that HHGE applications for disabilities or albinism could have a negative impact on the societal acceptance of individuals with these conditions.
- Conversely, an overwhelming majority rejected this notion, indicating that the purpose of the technology was not to foster discrimination but to improve the health and well-being of society. This includes the prevention of serious health conditions that have a significant impact on quality of life.

- For some participants, it was about having empathy and recognising the daily hardships faced by individuals with these conditions, who were in an unfavourable position. As such, HHGE was perceived as a means to alleviate their struggles.
- Additionally, the participants argued that discrimination is a distinct social issue and should not overshadow the primary purpose of the technology, which is to improve societal well-being and enhance the quality of life.

*Conclusion:* The informed South African public supports the use of HHGE to prevent serious genetic health conditions that are life-threatening and significantly impact the quality of life. However, ensuring that equitable access to the technology is a fundamental priority. In this regard, proactive governmental intervention may be required to mitigate the risk of exacerbating socio-economic disparities. Additionally, societal concerns, such as discrimination, should be addressed separately from the primary purpose of HHGE.

*SRQ 2 What is the informed South African public perspective on the use of HHGE to enhance immunity against infectious diseases?*

This research question was addressed by Theme 1 (The potential benefits of HHGE) and Theme 2 (Future implications for natural immune responses).

*Theme 1: The potential benefits of HHGE*

The informed South African public asserted that HHGE applications to impart immunity against infectious diseases should be permitted due to their potential benefits for the prospective individual and society.

*Benefits for the prospective individual*

- HHGE could be utilised to confer resistance to severe infectious diseases that are life-threatening, significantly impact the quality of life and are not always preventable. Consequently, diseases like TB and HIV/AIDS were highlighted as sufficiently severe to justify HHGE applications.
- TB was regarded as life-threatening due to its capacity to spread to other vital organs and the emergence of drug-resistant strains, which could elevate the risk of mortality. Although ARV therapy may extend the life expectancy of individuals with HIV/AIDS, participants still perceived it as a chronic and potentially fatal condition. Conversely, other infectious

diseases, such as the flu or common cold, were not deemed severe enough for genome editing interventions.

- Despite the availability of medical treatment, participants supported HHGE for severe infectious diseases due to their impact on the quality of life. Some participants emphasised that while certain conditions are treatable, the quality of life remains compromised. For example, drug-resistant TB requires a prolonged period of treatment, with increased associated costs. HIV/AIDS was viewed as particularly severe due to its impact on physical well-being (such as weakening the immune system and increasing susceptibility to other diseases) and the lifelong dependence on medical treatment.
- The participants also indicated that certain infectious diseases, particularly HIV/AIDS, are "not always preventable," as transmissions could occur through sexual assault, from mother-to-child, blood transfusions or accidental exposure to infected bodily fluids. In the South African context, it was also noted that prevention efforts may be ineffective in rural areas, where access to adequate healthcare facilities is limited, reinforcing the need for alternative solutions, such as HHGE.

*Benefits for society*

- The participants agreed that HHGE may be useful in reducing serious infectious diseases that were epidemic in South Africa (such as TB, HIV/AIDS and COVID-19). These diseases were interpreted as a significant societal threat, considering their high mortality rates and widespread impact. Thus, it was crucial to focus on health challenges that were unique to South Africa ('Country-specific' context)
- For the participants, HHGE could be used to improve public health and well-being by mitigating the burden of easily transmissible diseases (such as TB, HIV and COVID-19). In this respect, TB was a focal point, due to its rapid spread in South Africa. Additionally, despite preventative efforts, HIV/AIDS remains a major epidemic, with new cases emerging annually. The absence of an HIV vaccine led some participants to view HHGE as a more promising means in combating the virus. COVID-19 was also acknowledged as a highly transmissible disease, and while vaccines may reduce severity, they do not eliminate transmissions.
- The participants envisioned that reducing the prevalence of serious infectious diseases using HHGE, could alleviate the burden on public healthcare resources and reduce state expenditure. They emphasised the impact that specific infectious diseases, like drug-

resistant TB, have on the South African healthcare system, particularly in meeting high demands for treatment, hospital care, and providing specialised treatment facilities. HIV prevention through HHGE was also viewed as a more viable method in reducing state expenditure, given the high costs of lifelong treatments for patients.

- An additional benefit for society was the ability of HHGE to reduce the economic burden of serious infectious diseases. Beyond healthcare, participants noted the potential for epidemics (precisely COVID-19) to disrupt economic stability, by reducing workplace productivity and increasing reliance on state resources, such as SRD grants.

*Theme 2: Future implications for natural immune responses*

The informed South African public asserted that HHGE for less serious heritable conditions may be excessive and could result in unintended risks, such as the loss of natural immunity.

- According to the participants, genome editing for less serious conditions (such as the flu or common cold) could interfere with natural immunity, in which case, the potential risks may outweigh the benefits.

- They acknowledged the body's innate ability to fight off infections, preferring the natural development of immune responses than genetic modifications.

- The evolutionary role of viruses in human development was also discussed, with some participants highlighting that interactions with may have led to revolutionary advancements, such as the CRISPR-Cas9 technology itself. As such, the participants expressed caution about accelerating evolution through genome editing, fearing the unintended consequences for prospective children.

- The long-term effectiveness of genetically engineered immunity was a key concern, with participants questioning whether it could be as effective as natural immunity in combating infections.

*Conclusion:* The informed South African public supports HHGE for severe infectious diseases, such as TB and HIV/AIDS, due to their life-threatening capacities and ability to impact the quality of life. They believed that HHGE may be advantageous in improving societal health and reducing state expenditure for prevalent and deadly diseases. However, they express reservations about HHGE for less serious diseases, fearing that this could have far-reaching consequences for natural immunity.

*SRQ 3: What is the informed South African public perspective on the use of HHGE to edit for genetic enhancements?*

This research question was addressed by Theme 5 (The right to autonomy) and Theme 6 (Going against nature).

*Theme 5: The right to autonomy*

The informed South African public contended that HHGE for genetic enhancements could undermine the autonomy of prospective individuals.

- According to the participants, allowing parents to genetically enhance their children's traits, such as intelligence, could inadvertently limit the child's future autonomy by steering them towards a predetermined career or life path, restricting their ability to exert free will.
- While participants acknowledged the significant role of parental guidance in a child's formative years, they questioned the limits of parental authority, arguing that it should not extend to decisions that permanently or irreversibly impact the child's future autonomy.
- For most participants, genetic enhancements lacked the necessary therapeutic justification, unlike interventions for critical health issues. In this case, most participants believed that the potential medical benefits would outweigh any possible concerns about limiting autonomy.
- The participants emphasised that identity formation and self-discovery rely on the ability to make independent decisions. They argued that genetic enhancements could limit a child's capacity to explore personal preferences and make independent life choices essential to forming a true identity.
- Some participants viewed genetic enhancements as a way of "programming" children to meet the expectations of parents. They feared that parents may use HHGE to enhance their own self-image or to impose their interests on their children, thus restricting their autonomy. As such, it was crucial for parents to allow their children to form their own identities rather than shaping them to fulfil parental expectations.
- Some participants also expressed concern about the potential "alienation" of children if genetic traits or characteristics differ significantly from those of the parents. They

emphasised that altering genetic traits could sever the biological connection between parents and their children, such which was essential for personal and familial identity.

- Further concerns were expressed about the inability of prospective individuals to provide informed consent, precisely to a procedure that could induce irreversible changes. They feared that the child may subsequently disapprove of the modification, or that it may not align with his/her future interests. Moreover, genetic enhancements, such as altering sexual orientation, could have certain societal, cultural or legal repercussions for the prospective individual, resulting in potential stigma or harm. As a result, the participants emphasised the importance of ensuring that prospective children retain the ability to make independent decisions, highlighting that informed consent was crucial for respecting their autonomy.

*Conclusion:* The informed South African public emphasised the importance of preserving the future autonomy of prospective individuals. They expressed concerns that genetic enhancements, especially for non-therapeutic traits could limit a child’s future ability to exercise free will and shape their own identity. They also highlighted the ethical challenge of making irreversible decisions for a future individual who cannot consent, and the potential societal repercussions.

### *Theme 6: Going against nature*

The informed South African public feared that HHGE for genetic enhancements could disrupt natural processes and produce negative consequences for individuals and society.

### *Heading down a slippery slope*

- The participants feared that allowing genetic enhancements for specific traits, like intelligence, could lead to more controversial applications, such as designer babies.
- There was also widespread concern about the potential challenges in setting clear ethical limits for genetic enhancements, or where to draw the line? The line may be more apparent where there is a clear health benefit. As such, some participants believed that HHGE applications for enhanced intelligence may be permissible for correcting low-level IQs or a learning disability, and so perceived as a form of “corrective therapy”. Conversely, concerns were raised about defining the ethical boundaries of these applications, as perceptions of average intelligence may change over time.

- A major concern among participants was the potential for HHGE to lead to the commodification of prospective individuals, treating them as objects with customisable features.
- Participants feared this could result in children being viewed as objects, leading to a loss of their inherent human dignity and altering the traditional parent-child relationship.
- The idea of "playing God" was discussed, with participants fearing that genome editing would allow parents to assume a divine role in creating their children, raising religious and moral objections.
- Participants also raised alarms about the potential resurgence of eugenic ideologies, warning that genetic enhancements to create the "most optimised" or "ideal" person could be a step towards modern-day eugenics.

### *Nature vs Nurture*

- The participants believed that both genetics (nature) and environmental influences (nurture) play an equally vital role in shaping an individual's personality and behavioural traits. They highlighted the intrinsic overlap between genes and the environment, arguing that genetic predispositions still depend on environmental factors for expression. Consequently, some participants viewed genetic enhancements as ineffective in guaranteeing specific traits, since environmental factors could enhance or reverse these influences.
- They believed that a balance between nature and nurture was essential in giving full effect to certain traits or talents, such as intelligence. For example, intelligence requires a level of hard work for success.
- Concerns were also raised that genetic modifications for intelligence could undermine certain environmental factors, such as hard work or personal effort. The participants perceived hard work as essential for personal fulfilment, intellectual growth and gaining recognition in society. As a result, they feared that success would be based on genetic predisposition rather than hard work.
- Despite acknowledging the role of genetics, they preferred a natural approach to personality development, emphasising good parenting, education and nurturing environments over HHGE.

*The loss of genetic diversity*

- The participants expressed that permitting HHGE for enhancements could lead to reduced genetic diversity. They feared that widespread genetic modifications may create a homogeneous society where individuals share similar traits, such as intelligence or physical appearance. Some warned that this could result in a society where distinct characteristics and individuality are lost.

- Many participants valued diversity as integral to the human experience, asserting that each person is designed to be different. They emphasised that diversity enriches human interactions and experiences.
- The participants indicated that diversity plays a crucial role in societal balance. They discussed how different personality types, such as introverts and extroverts, complement each other and contribute to a well-functioning society.
- There was concern that genetic enhancements may prioritise intelligence at the expense of other valuable skills. If intelligence based enhancements were favoured, creative and artistic fields may suffer from reduced interest, potentially limiting the diversity of professions and talents within society.
- They highlighted the potential unintended consequences of modifying certain traits. For example, reducing aggressiveness might also decrease competitiveness, a trait often linked to success in fields like sports and academia.
- Genetic diversity was also linked to greater resilience against diseases. They argued that genetically homogeneous populations may face higher mortality rates, as seen in the COVID-19 pandemic. Genetic variation was viewed as essential for adaptability and survival, allowing populations to more effectively combat infectious diseases.

*Conclusion:* The informed South African public were concerned that HHGE for genetic enhancements could disrupt natural processes, leading to major societal consequences. They feared that genetic enhancements could lead to the commodification of children, the rise of eugenic ideologies, and the loss of individuality, as well as the potential for a homogeneous society. Participants emphasised the importance of balance between nature and nurture, believing that both genetic and environmental factors are essential in shaping human traits. They also expressed concerns about the impact on genetic diversity, which they saw as crucial for societal well-being and resilience against diseases.

*SRQ 4 :Why did the informed South African public change their opinions during the study?*

This research question was answered by Theme 7 (Ambiguity in reasons for opinion changes).

*Theme 7: Ambiguity in reasons for opinion changes*

- There were notable discrepancies between the quantitative (survey) and qualitative (discussion) data. For example, some participants' opinions changed before the deliberations even began, without clear explanation, making it difficult to identify the factors influencing their opinions.
- Many participants did not explain why their opinions had changed, and in some cases, the qualitative data (discussion transcripts) did not reflect the shifts observed in the post-surveys. For example, some participants expressed a stronger or different position in discussions compared to their pre-survey responses without acknowledging the reasons behind the change.
- Even when participants stated that their opinions had changed, the surveys often did not capture these changes, or the reasons for these shifts were unclear. In some cases, changes in opinion seemed to happen prior to the deliberations, while others occurred without explicit support from the discussion content (transcripts).

*Conclusion:* The study found that while participants' opinions on HHGE changed during the deliberations, the reasons behind these changes remained unclear. Inconsistencies between survey responses and discussion content made it difficult to determine the specific arguments or factors driving these changes, highlighting challenges in understanding how deliberation influences opinion changes.

*(c) Limitations & Future Scope*

The following limitations were noted, and the remedies to these limitations may constitute future avenues of study:

- The deliberate public engagement studies gathered participants based solely on diversity, and not diversity with a consideration of a sufficiently large sample size, therefore the raw data obtained from these sessions is prone to reduced generalisability.
- Statistical analysis, such as a paired t-test, was not utilised in the assessment of changing opinions.

- Thematic analysis is characterised by themes that are heavily subject to the researcher's interpretation, making theme formulation non-uniform and difficult to replicate should the study be expanded on by other researchers.

In evaluating these limitations, possible areas of interest for future research include integrating statistical analysis to numerically reinforce conclusions in terms of opinion change, and to ensure a sufficient sample size is considered so as to obtain raw data that is statistically representative of the population. Finally, it is suggested that the further research be conducted utilising thematic analysis, which would serve to fortify themes that are currently developed and to incorporate new themes, and the utilisation of different methods of analysis in the pursuit of unifying findings.

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29 March 2021

**Prof Donrich Willem Thaldar (59413)**
**School Of Law**
**Howard College**

**Dear Prof Thaldar,**

**Protocol reference number:** HSSREC/00002595/2021
**Project title:** A virtual deliberative public engagement study on heritable genome editing among South Africans
**Non-Degree**

## Approval Notification – Expedited Application

This letter serves to notify you that your application received on 12 March 2021 in connection with the above, was reviewed by the Humanities and Social Sciences Research Ethics Committee (HSSREC) and the protocol has been granted **FULL APPROVAL**.

**Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.**

This approval is valid until 29 March 2022.
To ensure uninterrupted approval of this study beyond the approval expiry date, a progress report must be submitted to the Research Office on the appropriate form 2 - 3 months before the expiry date. A close-out report to be submitted when study is finished.

All research conducted during the COVID-19 period must adhere to the national and UKZN guidelines.

HSSREC is registered with the South African National Research Ethics Council (REC-040414-040).

Yours sincerely,

[redacted]

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**Professor Dipane Hlalele (Chair)**

**/dd**

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YAKWAZULU-NATALI

Prof Donrich Willem Thaldar (59413)
School Of Law
Howard College

Dear Prof Donrich Willem Thaldar,

**Original application number:** 00011487
**Project title:** A virtual deliberative public engagement study on heritable genome editing among South Africans
**Amended title:**

## Exemption from Ethics Review

In response to your **amendment** application received on 22 February 2022 , your school has indicated that the amendment has been granted **EXEMPTION FROM ETHICS REVIEW.**

Any alteration/s to the exempted research protocol, e.g., Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through an amendment/modification prior to its implementation. The original exemption number must be cited.

For any changes that could result in potential risk, an ethics application including the proposed amendments must be submitted to the relevant UKZN Research Ethics Committee. The original exemption number must be cited.

In case you have further queries, please quote the above reference number.

**PLEASE NOTE:**
Research data should be securely stored in the discipline/department for a period of 5 years.

I take this opportunity of wishing you everything of the best with your study.

Yours sincerely,

[redacted]
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**Mr Matthew Blain Kimble**
**obo Academic Leader Research**
**School Of Law**