Towards Equitable Genomics Governance in Africa: Guiding Principles from Theories of Global Health Governance and the African Moral Theory of Ubuntu

Nchangwi Syntia Munung[1,2], **Jantina de Vries**[1], **Bridget Pratt**[3]

[1]Department of Medicine, University of Cape Town, Cape Town, South Africa

[2]Division of Human Genetics, Faculty of Health Sciences, University of Cape Town, Cape Town, South Africa

[3]Centre for Health Equity, School of Population and Global Health, University of Melbourne, Melbourne, Australia

Abstract

The post-genomics era promises a revolution characterised by precision medicine and the integration of genomics into almost every area of biomedical research. At the same time, there are concerns that if care is not taken, the genomics revolution may widen global inequities in science and health. In Africa, these concerns are primarily linked to the underrepresentation of African populations in genomics research, limited genomics research capacity in Africa and associated macro-level justice issues such as benefit sharing, inequitable international research collaborations, and the contribution of genomics to the health and research priorities of Africa. Addressing these concerns requires an in-depth reflection on how the ideals of global justice and equity may be advanced in genomics research. To contribute to the limited but growing scholarship on global genomics equity, especially in the African context, we performed a conceptual analysis of three accounts of justice and governance namely, *Ubuntu*, Shared Health Governance and Global Governance of Health, with the aim of identifying principles that could inform genomics governance in Africa. We used a convergence approach in the conceptual analysis, resulting in the identification of nine principles namely: solidarity, furthering the ideals of health justice, reciprocity, shared decision-making, shared resources, shared responsibility, mutual trust, transparency, and mutual collective accountability. Examples of how the principles may be applied are provided. We recommend that these principles should form the foundation of any mechanism that seeks to systematically advance justice, fairness and equity in genomics research in Africa and more broadly, global health and science equity.

Keywords

Genomics; Governance; Global health justice; Equity; Africa; Research ethics; Bioethics

Corresponding Author: Nchangwi Syntia Munung, Department of Medicine, University of Cape Town, Cape Town, South Africa, nchangwisyntia@yahoo.com.

Introduction

The completion of the human genome project (HGP) was a significant milestone in the biomedical sciences and it ushered humankind into a post-genomic era with promises of a genomics revolution and precision medicine. At the same time, there are concerns that if care is not taken, populations in Low and Middle-Income Countries (LMICs) may not benefit from the genomics revolution which may in turn widen global inequities in science and health. Fears of a global genomics divide are ascribed to a number of scientific and equity concerns. Firstly, there is an under-representation of African populations in genomics studies. Given the human genetic diversity in Africa, failure to include African populations in genomics research will mean that genomics studies conducted in other parts of the world may not be generalizable to African populations[1]. Secondly, the limited capacity for genomics research and genomics medicine in Africa could hamper the implementation of genomics research and access to genomics medicine in Africa. Put together, the concern is of a global genomics equity divide that will widen science and health equity between high income countries (HICs) and African countries. Thirdly, the growing recognition of the value of Africa's human genetic diversity in elucidating the role of genes in disease and health has seen a strong interest in mining African genetic data for global interest. Yet it is unclear if there are plans for ensuring access to genomics medicine and interventions by populations in Africa[2].

To prevent a global genomics equity divide, a number of genomics research initiatives have been set up in Africa to ensure the representation of African populations in genomics studies and to build capacity for genomics research in Africa[3]. These genomics initiatives are 1) primarily funded by institutions in the global north; 2) involve research collaborations with institutions in HICs; 3) require the establishment of biobanks for long term storage of biospecimen; 4)involve the deposition of research data in genetic databases such as the European Genome-Phenome Archive and; 5) have the advancement of global equity in genomics as one of their axioms. Nonetheless, limited human and infrastructural capacity for genomics research on the continent implies that African scientists involved in these projects would likely send biospecimens to the global north for genetic sequencing. This heightens fears of exploitation of African researchers and study populations that have traditionally characterized international health research in Africa[4]. Secondly, while genomics data sharing is becoming a global norm for both scientific and ethical reasons, many African institutions have limited bioinformatics and data science capacity to enable them to fully utilise and analyse the primary data that they will generate as part of these genomics initiatives[5]. This undoubtedly creates an uneven playing field in terms of power dynamics for genomics research collaborations in Africa[6]. Thirdly, given the profile of the disease-burden in Africa, there are concerns about whether limited resources should be directed at research priorities for conditions that are a major public health burden in sub-Saharan Africa (e.g. HIV/AIDS, tuberculosis and malaria) or more broadly towards understanding genetic risk factors for other diseases. If not adequately addressed, these factors may limit or slow down efforts aimed at advancing global equity in genomics.

More recently, stakeholders in genomics research in Africa have begun to reflect on how structural inequities in global health and biomedical research in general could shape the

operations and implementation of genomics initiatives in Africa[7], including what it means, in practice, to advance the ideals of global justice, fairness and equity in genomics. One approach has been to design equitable governance models or frameworks[8] that could provide guidance on how concerns related to the potential of genomics to widen global health inequities, limited genomics research and biocomputational capacity in Africa and the possibility of exploitation of African researchers and study populations, could be best addressed. A limitation of the frameworks that have been proposed thus far, is that that the tend to rely heavily on the collective intuition and experiences of some stakeholder groups, mainly African researchers, and it is often not clear, at least from a conceptual standpoint, how the recommended principles and practices were derived. In this paper, we normatively explore what the governance of genomics ought to look like if it were to advance global genomics equity. We did a conceptual analysis of three accounts of justice and governance, with the goal of identifying principles that should inform equitable genomics governance in Africa. Based on the outcome of the conceptual analysis, we provide examples of how the principles can be applied to genomics research in Africa. We conclude with limitations of our approach and future directions for more in-depth exploration.

Principles for Genomics Governance in Africa: A Conceptual Approach

To identify principles that should inform fair and equitable governance of genomics research in Africa, we conducted a conceptual analysis of two theories of global health justice and the African communitarian ethic of Ubuntu. The conceptual analysis followed the convergence method[9] which consists of three broad stages[10]: the *synthesis preparation* phase (extraction and summary of parts of the theories of interest);the *synthesis phase* (comparing the different theories to identify areas of convergence and divergence); and the *synthesis refinement* phase whereby the outcome of the synthesis (in phase 2) is further examined for theoretical insights on how it relates to the moral problem of interest (in our case, equitable governance of genomics). The advantage of the convergence method is that it often leads to solutions that are less contentious, compared to those developed from a single theory[11].

Synthesis preparation: Extraction of principles from the three theories of Justice and Governance—Given that genomics has been linked to global health and global health equity[12], theories of global health justice are a logical starting point for developing ethical guidance on the equitable governance of genomics. This is because they provide a moral structure of what ought to be done to achieve fairness and equity in global health[13]. Recent conceptual work has also linked global health justice to equitable research governance[14]. We opted to focus on two theories of global health justice that seemed most pertinent to our work, namely: Global Governance of Health[15] and Shared Health Governance[16]. These theories were prioritised for four main reasons: 1) they link the promotion of global health justice to governance; 2) their development takes into account power differences between LMICs and HICs and the impact that it has on global health partnerships; 3) these theories consider research as a critical activity for addressing health inequities; and 4) shared health governance (SHG) has been applied to the governance of global health research in LMICs [17].

As governance mechanisms tend to be more widely accepted if they are informed by the principles, values and cultural norms shared by persons involved in a joint activity or in the community where they will be used, we also included Ubuntu in our conceptual analysis. Ubuntu is an African communal theory of justice and fairness and a communitarian ethic. This is because our goal was to develop an account of genomics governance that would be considered acceptable by genomics stakeholders in Africa. Equally, there are growing arguments that African perspectives or moral thought are necessary when framing discussions around the ethics of global health research in Africa[18]. Ubuntu does not specifically refer to global health. It is an African moral theory of humanness, the way of life of people in sub-Saharan Africa, a communitarian ethic, and a theory of justice and fairness[19] that has historically informed governance in traditional sub-Saharan Africa[20]. However, Ubuntu is now emerging as a moral theory of interest that could inform debates on the ethics of genomics research in Africa[21]. It is worth noting that in this study, our objective was to use existing conceptualisations of Ubuntu (as an ethic, a theory of justice, an African philosophy and a way of life), to highlight how it could contribute to the genomics governance literature. We did not seek to enter the philosphical debate on what exactly Ubuntu should be, based on these different conceptualisations. The principles advanced in the three selected theories are briefly presented.

Global Governance of Health—Global Governance of Health (GGH) is a theory of global health justice that was developed in response to challenges faced in the governance of global health, including the impact of scientific and economic power differentials between LMICs and HICs[22]. Key principles promoted in GGH include transparency, deliberative decision-making, honesty, efficiency and mutual collective accountability (Figure 1).

In addition to these principles, GGH puts forth three strategies for advancing equity in global health namely: capacity building, health priority setting and stakeholder engagement[23]. A bottom-up approach to capacity building is recommended, whereby LMICs, through empirical evidence, will articulate their capacity building needs and international agencies would then support them achieve their health needs in a manner that is sustainable. Similar to capacity building, it is recommended that LMICs take responsibility for identifying their health priorities and that international assistance should be directed towards major causes of mortality, morbidity, disability and structural inequalities in health between population groups[24]. This recommendation is based on the observation that global health programs often fail to align their activities with local health needs, and this could slow down efforts aimed at advancing global health equity. The third strategy is stakeholder engagement that is grounded in consensus-driven dialogue[25].

Shared Health Governance—Like GGH, Shared Health Governance (SHG) was developed in response to failures by global health actors to take up their responsibilities and implement policies that actualise the public moral norm of health equity[26]. SHG makes proposals on appropriate governance arrangements necessary for promoting justice and fairness in global health. The main principles promulgated by SHG are furthering the ideals of health justice, shared sovereignty, shared resources, mutual collective accountability, and

shared responsibility. These principles and how they apply to global health research (Figure 2) have been previously described[27].

Ubuntu—Ubuntu is an African moral theory of humanness, the way of life of people in sub-Saharan Africa, a communitarian ethic, and a theory of justice and fairness[28] that has historically informed governance in traditional sub-Saharan African settings[29]. Notably, whilst the word Ubuntu is used predominantly in South Africa, there are equivalent philosophies in many sub-Saharan African communities[30], thus, its principles are likely to appeal to many populations across sub-Saharan Africa.

Compared to SHG and GGH, Ubuntu has not been extensively applied to global health research and its normative contributions to the governance of global health research are yet to be explored. Nonetheless, as an indigenous African theory of justice and fairness and a communitarian ethic, some scholars have described the values and principles espoused in Ubuntu. They include solidarity, reciprocity, deliberative decision-making, mutual trust, inclusivity, friendliness, harmony, generosity; mutual caring; and compassion[31]. Ubuntu is also about humanness and a way of life of people in sub-Saharan Africa (for example, it is common to say someone has Ubuntu). As such, some of the above principles, such as friendliness and generosity, are the qualities of a person who has Ubuntu[32]. For the purposes of this study, our interest in Ubuntu relates to how it was conceptualised as a theory of justice, fairness and a communitarian ethic, and the extent to which it may inform governance of genomics[33]. We therefore excluded principles/values that primarily speak to the moral qualities of an individual.

Synthesis of SHG, GGH and Ubuntu: Points of Divergence and Convergence
—In the synthesis preparation phase[34] (extraction and summary of principles espoused in SHG, GGH ad Ubuntu), we identified a total of eleven principles across the three theories of justice (Fig, 1–3; Table 1). Six of these principles were promoted by all three theoretical accounts directly or indirectly, either by using the same or different terms (but with similar meaning). These were: shared decision-making, transparency, shared resources, shared responsibility, trust and accountability (Table 1). Three other principles (furthering the ideals of health justice, solidarity and efficiency) were directly or indirectly advanced by two of the three theories, while two principles (reciprocity and honesty) were identified by only one account.

Solidarity and reciprocity are directly promoted by Ubuntu only. However, SHG is "fundamentally synergistic with solidarity" in that it promotes solidarity at the global level[35]. Equally, earlier accounts of SHG made a case that the public moral norm as one that incorporates the interest of a person in relation to society[36]. However, it is cautioned that SHG may not be as communitarian as conventional solidarity[37].

The principle of furthering the ideals of health justice is advanced in both SHG and GGH but not Ubuntu. As an African theory of justice and fairness, Ubuntu does not set out to directly address issues of global health. However, in many African communities, each member of the community, in line with the principle of solidarity, will be expected to contribute to the common good and the flourishing of all members of the community[38].

Also, given that equity-oriented systems are at the core of Ubuntu, it is likely that if it were applied specifically to global health, it would advocate for health equity[39]. Also, furthering the ideals of health justice is not directly stated as a principle in GGH, however, the very goal of GGH is to suggest equity-based governance norms that would collectively shape the health of the world's population[40].

Mutual trust is not directly listed as a principle in SHG. Yet, in advocating for the principles of deliberative decision-making, transparency, accountability and shared responsibility, Jennifer Ruger suggests that these principles play an essential role in building trust between global health actors and that trust is sustained when global health stakeholders honour reciprocity obligations[41].

Ultimately, nine principles are supported across the three accounts, directly or indirectly (as is the case with solidarity, reciprocity, furthering the ideals of health justice and mutual trust), Only these nine principles were considered is core principles required for the development of ethics-based governance of genomics. The principles of honesty and efficiency were not taken forward as core principles as they are encompassed by at least one of the key nine principles. For example, the principle of efficiency, as described in GGH, is about effectively using resources and ensuring that activities are coordinated to avoid duplication. In SHG, efficiency is considered important in guarding against waste of limited global health resources and it is argued that shared decision-making can lead to gains in efficiency[42]. The efficiency principle can therefore be linked to the principles of shared resources, shared responsibility, and shared decision-making. Honesty, on the other hand, is about transparency, free flow of information and civic participation and therefore speaks to the principles of trust, transparency and shared decision-making.

Table 1 presents points of convergence and divergence of the principles in the three theories. Where the principle is directly mentioned in the one of the three theories or accounts, we have indicated that with a tick. Where the principle is only indirectly mentioned, we have provided a brief description of how it relates to the principles directly mentioned in one of the three theories or accounts. Where the theory does not speak about the principles, we have left a blank space.

Synthesis refinement: Recommended principles for the governance of genomics in Africa—In line with the convergence approach, only principles supported across all three frameworks (Table 1) were considered core principles for advancing justice, equity and fairness. In Table 2, we list these principles and provide a brief description of the principle as it is used in the different theories. We also make suggestions for how the principles can be operationalised in genomics research in Africa. Our suggestions are informed by the ethics literature on genomic research in Africa[43] and our experiences in developing governance frameworks for genomics research in Africa as part of the Human Heredity and Health in Africa (H3Africa) consortium and global health projects in Africa[44]. These different bodies of work were informed by the perspectives of different stakeholder groups mainly African researchers, policy makers, members of research ethics committees and funders of genomics research in Africa.

Discussion

Governance is a value-laden concept[45] and while it is very broad in scope, the foundation of any governance mechanism is the principles that are shared and considered good practice by persons involved in a joint activity[46]. The aim of our study was to identify principles that should inform equitable governance of genomics research in Africa. To do so, we relied on two accounts of global health governance (SHG and GGH) and Ubuntu, an African Communitarian ethic and a theory of justice and fairness. Using the convergence approach, we identified nine principles (Table 2) from these three accounts that can inform the equitable governance of genomics research in Africa. Our recommended principles and recommendations on how they may be applied will help guide existing and future genomics initiatives in Africa to more systematically advance global health and science equity.

While some of the principles are defined or described somewhat differently by the three theoretical accounts, similarities exist in their definitions or the way they are described. These similarities are what were adopted when describing the core aspects of such principles. It is possible that there will be differences between the accounts' descriptions of how certain shared principles may be actualised in global health research. For example, in SHG and GGH, the inclusiveness requirement emphasises the equality of all stakeholders. Ubuntu, on the other hand, recognises the class structure[47] but advocates for substantive representation – which involves giving equal voice to different groups (for example differing according to age, clan or social status) within the community and ensuring that their perspectives are taken into account in decision making[48]. While this may signal a different implementation, they are not at odds, as the end goal is to ensure inclusive participation in decision making. Where tensions are identified, conceptual and empirical work should examine which approach should be considered best practice.

Many theories and accounts of justice and global health exist[49] and perspectives on African relationism, of which Ubuntu is part, are constantly evolving[50]. In our work, we engaged more narrowly with contributions in African relationism that describe an Ubuntu philosophy. How these evolving perspectives align with or differ from our analysis should be further explored. The aim of our study was to start to address the gap between theory and practice in terms of governance of genomics research in Africa.

Finally, we note that further work is needed to identify how each principle may be applied to the governance of genomics research in Africa. This paper has made some initial suggestions for what upholding each principle could mean in practice (Table 2); more conceptual and empirical work is needed to translate the principles into specific guidance for governance. It is possible that when that guidance is derived, recommendations for upholding one principle may conflict with recommendations for upholding one or several of the other principles. Identifying these tensions and developing additional guidance on how to navigate them is another important avenue to explore in future work. Ultimately, the principles identified through the conceptual analysis of GGH, SHG and Ubuntu can be used to develop best practice guidance for the equitable governance of genomics research in Africa and provide a framework for how different stakeholders in global health research can enter into a genuine dialogue on equity-oriented genomics research in Africa.

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Biographies

Nchangwi Syntia Munung is a Postdoctoral research fellow at the Division of Human Genetics, University of Cape Town. She combines both normative and empirical bioethics methods to explore issues of equity and fairness in global health research and emerging biotechnologies.

Jantina De Vries is an Associate Professor in Bioethics in the Department of Medicine at the University of Cape Town. Her research interests include the ethics of genomics research in Africa, as well as issues of fairness and justice in international collaborative health research.

Bridget Pratt is an ethics researcher and the Mater Lecturer in Healthcare Ethics at the Queensland Bioethics Centre at Australian Catholic University. Her research interests include the ethics of global health research and health systems research, with a focus on social and global justice.

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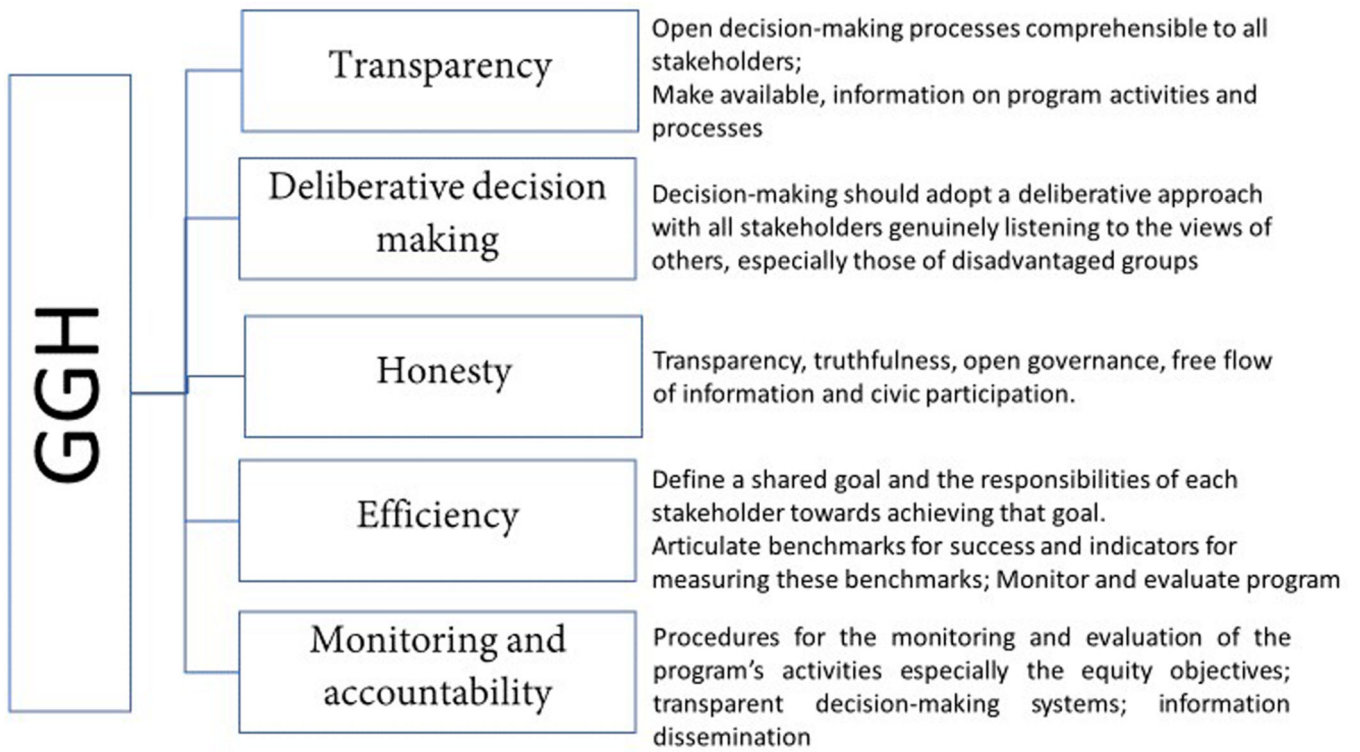59. Gostin & Friedman, op. cit. note 15, p1–75;Ruger, op. cit. note 16, p32–45.

Figure 1:
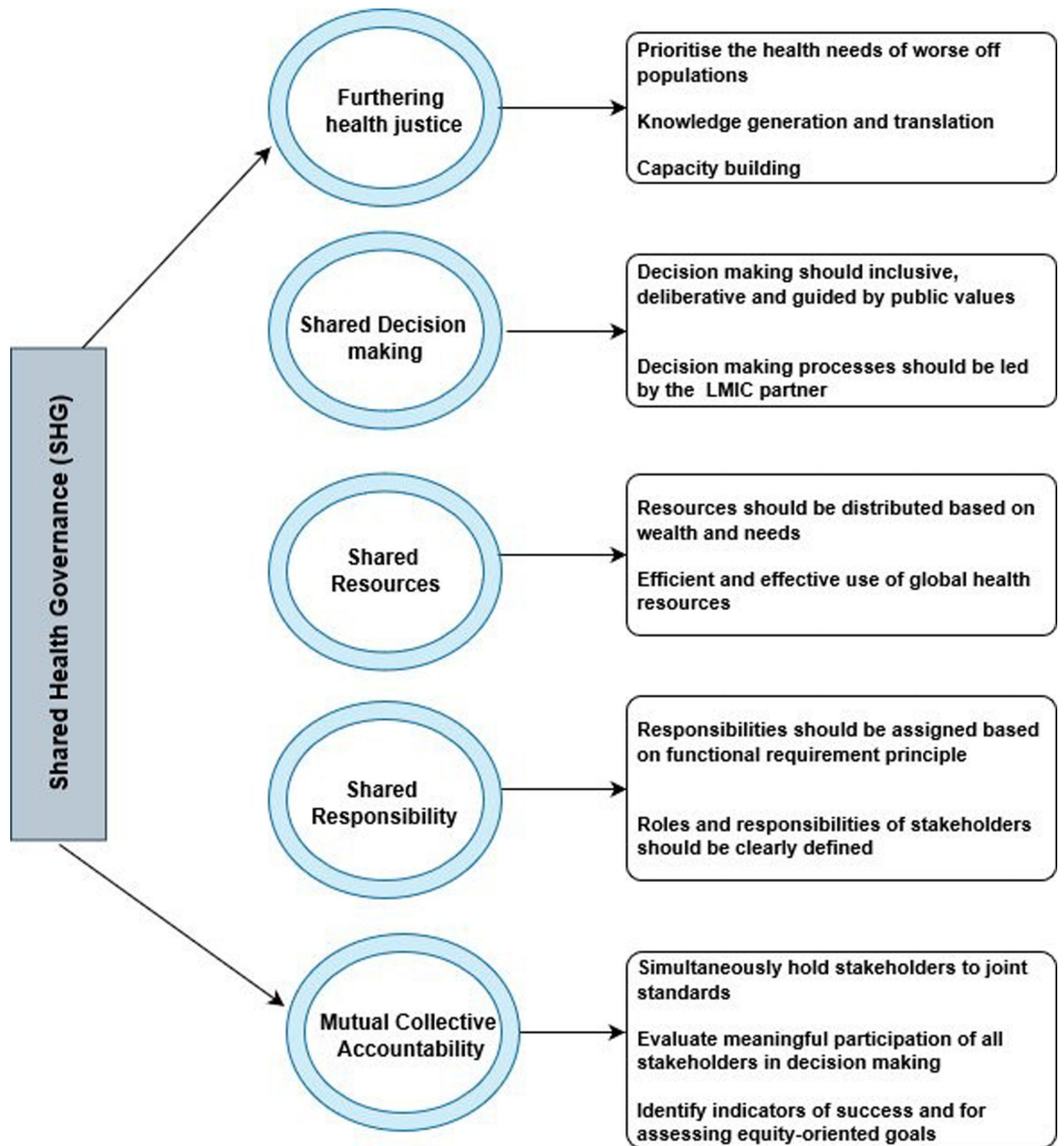Principles supported by Global Governance of Health

Figure 2:
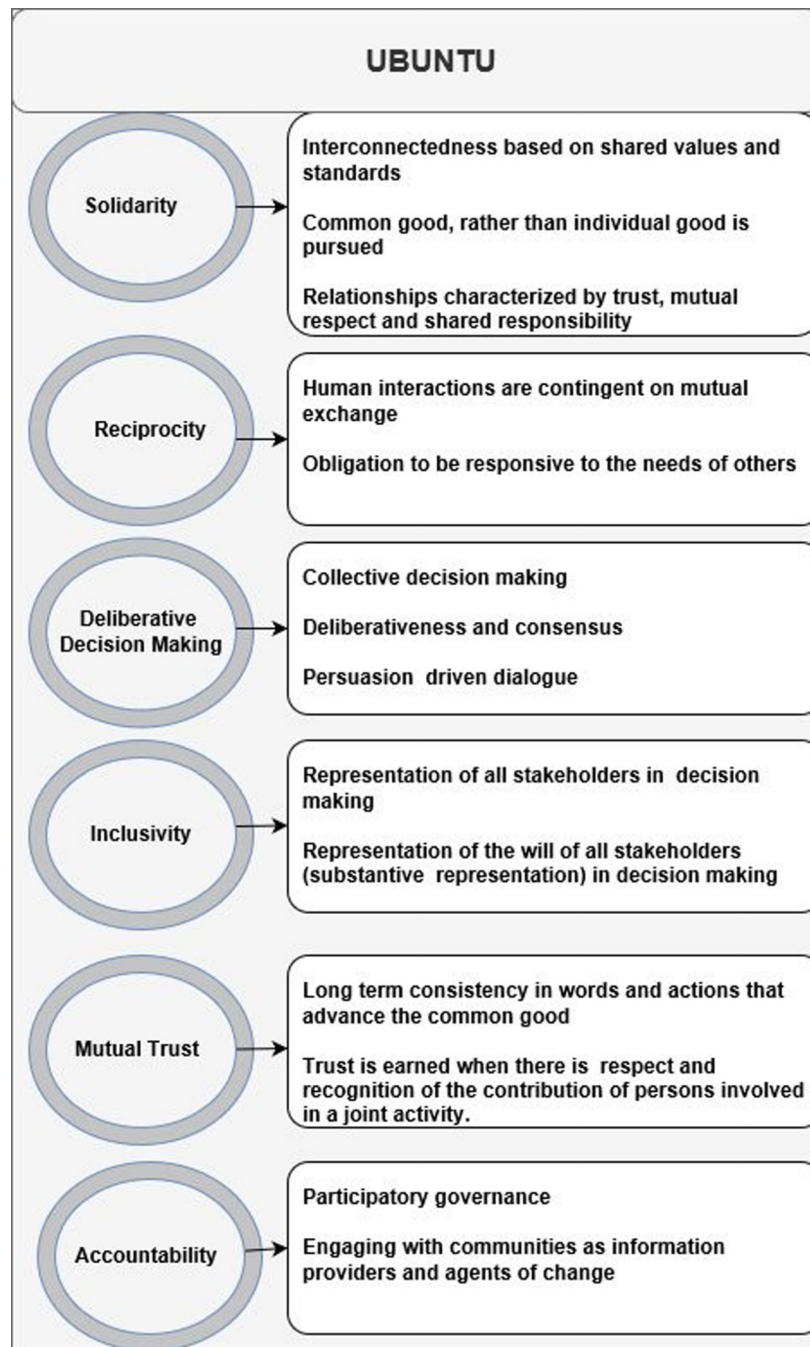Principles promoted by shared health governance as applied to research

Figure 3:
Principles Promoted by *Ubuntu* ethic

Table 1:

Points of convergence (and divergence) between GGH, SHG and *Ubuntu*

Principle	Ubuntu	GGH	SHG
Furthering the ideals of health justice		✓	✓
Honesty		✓	
Solidarity	✓		Indirectly through reflective solidarity
Shared decision-making	✓	✓	✓
Transparency	✓	✓	✓
Accountability	✓	✓	✓
Mutual Trust	✓	Indirectly through its honesty and transparency principles)	Indirectly through deliberative decision-making, transparency, accountability and shared responsibility
Shared resources	✓	Indirectly through efficiency requirement	✓
Efficiency		✓	Indirectly through shared resources, mutual collective accountability and shared responsibility
Reciprocity	✓		
Shared responsibility	✓	Indirectly through its accountability principle	✓

Table 2:

Principles that should inform the governance of genomics research in Africa and how they could inform ethical guidance for fair and equitable governance of genomics research

Principle	Brief description	Examples of how the principles may be applied to genomics research in Africa
Solidarity	Communal unity based on shared goals, values, responsibilities and standards[51]. Solidarity is a key in African communitarianism and it is the realisation that one's capability depends on others and that the common good should be pursued rather than the individual good	Sub-Saharan Africa disproportionately bears the global burden of disease, especially infectious diseases. Human genomics research has the potential to reduce global health inequities for instance through the identification of potential drug development targets or through the development of pharmacogenetic indicators to guide drug dosing. However, many of the emerging genomics technologies and innovations are largely unavailable in African countries and other LMICs. This global divide in access to genomics advances for health and health research may widen global health inequities and perpetuate a genomics divide. To prevent or narrow such a divide, investments in genomics research and genomic medicine are needed in sub-Saharan Africa. This could be made possible through supporting the exchange of genomics services, technology and expertise between HICs and African countries; strengthening genomics research and genomic medicine capacity in Africa; aligning genomics research in Africa to the health and research priorities of sub-Saharan Africa and supporting African countries to develop capacity for the translation of genomics research. For this to be possible, and through equitable economic investment, HICs and relatively wealthier LMICs with high genomics capacity should support sub-Saharan African countries to develop their genomics research and services so as to ensure equitable global distribution of genomics medicine and research. International support to sub-Saharan Africa comes with the need for sub-Saharan Africa to also share expertise and resources with other regions of the world so as to collectively contribute to the development of genomics medicine and research. One way is for populations in Africa to participate in genomics studies and be willing, to promote the global good, to consent to genetic data sharing. Similarly, African researchers have an obligation to share genomic data for the global good. This is because Africans are more genetically diverse than any other population globally. Therefore, genomics studies in African populations would facilitate scientific discovery on genetic factors that contribute to disease susceptibility, not only in African populations but globally.
Reciprocity	Human interactions are generally contingent upon mutual exchange[52].	Globally, genomics stakeholders have a shared responsibility to exchange experiences, genomic knowledge and genetic resources for the advancement of the common good. Mechanisms and processes for ensuring fair and equitable access to and distribution of the benefits of genomics research by study populations in Africa should be clearly defined. Genomics researchers in Africa should intentionally seek ways of addressing the research expectations of their study participants/population e.g. through feedback of research findings, prioritising research that directly addresses the burning health needs of study populations.
Furthering the ideals of health justice	Global health programs should aim to reduce global health inequities by improving the health of the global poor[53].	Genomics research programs in Africa should aim to reduce global health inequities by 1) prioritizing the health needs of populations in Africa; 2) building genomics research capacity in Africa; and 3) supporting the translation of genomics research findings. African governments should work together with other stakeholders to define national genomics research priorities. At the continental level, programs charged with the responsibility to promote research and development such as the African Union Development Agency New Partnership for Africa's Development and the African CDC should work with the different stakeholders to identify priorities for genomics at the African continental level. Funding and grant calls should be directed at identified priorities of genomics research in Africa.
Shared decision-making	Decision-making should be inclusive, deliberative, consensus-driven and guided by acceptable public values and moral norms[54].	Democratic and substantive representation of all stakeholders is required in decision-making processes within genomics consortia. This demand giving equal voice to all stakeholders, especially groups that are vulnerable and have traditionally been left out of decision-making processes, including for instance (representatives of) study populations, patients advocacy groups, junior researchers and researchers in Africa. Public participation should be sought when developing genomics policies, especially policies that directly affect the public including for instance secondary uses of their data or commercial use of data.
Shared resources	Resources should be equitably distributed based on the needs and relative wealth of each stakeholder group[55].	No nation, population or stakeholder group should hoard genetic resources (data, samples) or products (IPs, publications etc) for their personal gain at the expense of others. Intellectual property models that do not serve as barriers toward access to genomics medicine and innovations should be prioritised. Secondary access to data and biospecimen should be done in ways that promote equitable access and use of data and samples by African researchers. Historical experiences of exploitation of African researchers in global health research collaborations has generated a need to seek ways of mitigating such exploitation in

Principle	Brief description	Examples of how the principles may be applied to genomics research in Africa
		ongoing and future genomics and global health research collaborations in Africa. One of the main concerns has been that African researchers tend to be limited in their involvement in actual research because funds are held by their collaborators in HICs, who then tend to make decisions on the contributions of their African collaborators. This has often meant that African researchers tend to be limited to collecting samples but not doing the actual genomics analyses. One possibly outcome of this is an inability to translate findings to the health research priorities in Africa. One way of overcoming this is for funding schemes for genomics research in Africa to be designed to allow for African researchers to lead research studies conducted in Africa and to have discretion over spending decisions. This indirectly gives them the opportunity to conduct genomics studies in Africa whilst building capacity on the continent. It also allows African researchers to focus on their research priorities rather than that of their collaborators.
Shared responsibility	The equity-oriented responsibilities of each stakeholder group should be assigned based on the functional requirements principle, i.e. based on the function that a stakeholder typically assumes [56].	Minimising possibilities of exploitation of African researchers and study populations and ensuring that genomics contributes to reducing global health inequities will first and foremost require that genomics research consortia identify and clearly describe the equity-oriented responsibilities of each stakeholder group (funders, African researchers, HIC research collaborators, study populations etc). Examples of such equity-oriented responsibilities include • Researchers in Africa should be responsible for designing and implementing genomics projects that address the health needs of African populations. • Funders should allocate resources towards research capacity building, research translation and genomics studies that address the identified health needs of populations in Africa. • Data and biospecimen access committees should prioritise research projects that have plans for long term collaboration with African researchers. • Secondary users of genomics data and samples from Africa should ensure that their research is also aligned with genomics research priorities in Africa. • Study participants should ideally consent to data sharing and there should be mechanisms in place to avoid exploitation of study participants. • Collaborators of African genomics researchers should ensure that when samples and data from collaborating sites are stored and used in their institutions, there are mechanisms in place to acknowledge and recognise the contributions of their African collaborators.
Transparency	Free and open flow of information amongst stakeholders[57].	Genomics initiatives should make available information on how on how key ethical and legal issues will be addressed. For example, information on who has custodianship of data and how IP rights would be distributed in the case of an innovation. Study communities should be provided with feedback on the use of samples and data and the outcome of genomics studies. Appropriate means of communicating with each stakeholder group should be identified.
Mutual Trust	Trust relates to the expectation that one can rely on another person's words and actions and that the person has good intentions to carry out their promises[58].	The processes and practices of genomics research in Africa should be designed such that there are mechanisms for fostering mutual trust between stakeholders, including but not limited to recognizing the contribution of all stakeholders, feedback of information on use of data and study outcomes, and involving study populations in decision-making on use of samples and genetic data.
Accountability	Stakeholders should be simultaneously held to joint standards and agree to their respective roles and responsibilities[59].	Genomics research programs should, in addition to the scientific goals, articulate their equity-oriented goals, including possible outcomes of these goals and how they will be monitored and evaluated. All stakeholders should have a common understanding of the equity-oriented goals of the project. The extent to which projects achieve their equity-oriented program goals should be monitored.