

Rethinking Value Pluralism in the Ethics of Sharing Benefits and Burdens in Collaborative Research

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Abstract

The paper argues for an ethical consideration of value pluralism, which advocates for consideration and respect of differing values that emanate from diverging contexts and positionalities. Advancements in medical health research has resulted in tremendous increase in national and international collaborations, though with exploitative tendencies. Exploitation in collaborative research is however, avoidable if expected research benefits and burdens are shared fairly. Power imbalance dynamics from global north to south impound the ethical principle of fairness. The appreciation of multiplicity of values/benefits that are distinct, creates room for an embrace of the principle of autonomy which safeguards exploitation, by appreciating heterogeneous identity.

Keywords: Benefit and burden sharing, Collaborative research, Exploitation, Fairness/Justice, Value pluralism, heterogeneous identity

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1. Introduction

Value pluralism, is a moral theory that admits to multiplicity of values within differing contexts for different categories of people, even within a shared moral event. It appreciates that differing contexts and situations have differing constructs that can be conceptualized as a value and/or of value. Global advancements in information computing and medical technology has recorded a tremendous increase of national and international health research with collaborative initiatives. These collaborating partnerships experience ‘dynamics that are reflective of power imbalances and persisting inequalities between north-south, public-private, or global – local collaborations’ which affects our valuing systems in return (Larkan et al, 2016:7). Power dynamics, ignorance, poverty compared to well-standing parties in collaborative research most often fuel exploitation. Some of the power packed discrepancies arise depending on who is funding the study and/or intellectual prowess that most often hinder the target community from negotiating for equity in sharing the benefits.

Nevertheless, collaborative research is laudable since it ‘supports co-creation, translation and exchange of new knowledge’ which is paramount in the improvement and sustenance of human persons’ well-being (Wine et al, 2017: 1). It follows that such collaborations between the global north (rich) and south (low resource) result in benefits and/or burdens but there is no equity in the outcomes. Compromise and disrespect of individual’s intellectual property rights, social value and constructs are components that ought to be adequately considered if fairness in benefits and burdens sharing principle is to be viable.

According to Human Genome Organization (HUGO),

A benefit is a good that contributes to the well-being of an individual and/or a given community (e.g. by region, tribe, disease-group...). Benefits transcend avoidance of harm (non-maleficence) in so far as they promote the welfare of an individual and/or of a community. Thus, a benefit is not identical with profit in the monetary or economic sense. Determining a benefit depends on needs, values, priorities and cultural expectations (HUGO Ethics Committee, 2000:4).

A benefit thus, goes beyond monetary claims. It is an innate self component that gratifies and enhances the sensual well-being of a human person, whereas, a burden can be conceptualized as anything that destabilizes the innate faculties of self. In most cases, researchers think of benefits from economic perspective that directly alludes to financial gain. It is rather not solely dependent on economic gains only but also on intrinsic motivations, like sharing of knowledge, authorship and access to health care among other gains. Such a concept warrants classifying both the act and process of benefit and burden sharing as both a subjective and social value, which is also a parameter of distributive justice, insinuating to plurality of values.

The principle of benefit-sharing pertains to the distribution of benefits and burdens emanating from the development activities and research undertaken in any given community (Simm, 2007). It involves not only the people carrying out the research but also those who have personally taken part in the research, such as research subjects and community members, active and non-active. Collaborative research has however, over the years been characterized by exploitative tendencies and skewedness to funding bodies’ demands, which is quite unethical (Millum, 2012). According to Wertheimer (1999), exploitation occurs when a collaborating party takes ‘unfair advantage’ of another party, and the community within which the research takes place. Exploitation can be avoided

if the expected benefits and burdens emanating from any collaboration are understood and shared equitably and/or fairly as understood by community gatekeepers.

People however, define value differently. For a healthy, busy and stable person, for example, health care is about convenience and access. This will be different for someone who is chronically sick and the poor. Further, in cases where a research is funded, researchers from developing countries may choose to enjoy several advantages that they perceive to arise from the offer, as values. Some of the perceived values might for instance include, the opportunity to conduct a health research, a prospect of engaging and sharing with other scholars intellectually, monetary gains, possible publications as well as the opportunity of meeting corporate social responsibility in the society among others. These values may not count as valuable to the research subjects the community and the research donor partners. The global north partners may embrace opportunities to share their scientific data, methods and experiences; financial gain; tourism and adventure among others, as values. Valuing systems are therefore dependent on more aspects other than sole materialism, up to including specific cultural, geographic, religious or other contexts and sensual perceptions important to human persons.

In arguing for value pluralism, this paper proceeds first, by evaluating the two international frameworks, that is, Responsiveness and fair benefits for sharing of benefits and burdens in collaborative research. Second, value pluralism advanced by Isaiah Berlin (1909-1997) is proposed as a worth component, since it appreciates multiplicity of values emanating from people's innate perceptions of wellbeing as well as their differing contexts and positionalities. The paper concludes its endeavor that centers the appreciation of heterogeneous identity in terms of values. It also act as a deconstruct of power dynamic and imbalances evident in collaborative research, towards preservation of one's autonomy and social justice.

2. Benefit Sharing Frameworks

2.1 Responsiveness to Healthcare Needs

The ability to improve health outcomes amongst people and populations internationally, has been a major goal in health research. Community and patient satisfaction which is directly linked to their values and expectations is an area of concern in collaborative research. Advances have been made to evade exploitative tendencies that emanate from such collaborations, especially where developed nations conduct research in low and middle income countries. Patient/research respondents' experiences and interpersonal relations with researchers from either the developed and developing countries are critical in safe-guarding exploitations that may be fueled by power packed imbalances/differentials.

In the year 2000, World health Organization (WHO), recognized the concern on practitioner and patient interaction within health systems and referred to it as responsiveness. Internationally, the Council of International Organizations of Medical Sciences (CIOMS) in collaboration with WHO clarified responsiveness, with the assertion that,

...“before undertaking research in a population or community with limited resources, the sponsor and investigator must make every effort to ensure that the research is responsive to the health needs and the priorities of the population or community in which it is to be carried out; and any intervention or product developed, or knowledge generated, will be made reasonably available for the benefit of that population or community” (CIOMS, 2002:16).

The counsel appeared appealing and prompted the World Medical Association version of the Helsinki Declaration (2008), to reiterate the concept, with simplicity. It noted that,

... “Medical research involving a disadvantaged or vulnerable population or community is only justified, if the research is responsive to the health needs and priorities of this population or community, and if there is a reasonable likelihood that this population or community stands to benefit from the results of the research.’

Responsiveness claim ensured that the community benefited or that there were higher chances of benefiting from the anticipated collaborative research. According to Williams (1994: 38), ‘a responsive health system contributes to health enhancement through enabling individuals to seek medical care earlier, it necessitates open interactions between patients and health care providers as well as enabling persons assimilate health information better.’ These health enhancements pass as values anticipated by the guiding organizations, though they remain blind to the immediate needs and values of the host research community. Nevertheless, the positive outcomes persuaded international ethical bodies to lean on responsiveness as a guiding ethical principle for conducting a research in developing countries.

Questions however, loom on what exactly qualifies as a ‘benefit’ to the research population and the researchers from both fronts. What are some of the parameters that would actually gauge that the research is responsive to the healthcare needs of the population in question? This follows from the fact that research is procedural, takes time and hence, the proposed benefits might be anticipatory and hypothetical. A fact that leaves room for a negative change, when the research is still underway. Further, values are plural and varied depending on the researchers and research subjects' contexts and positionalities, a factor that responsiveness framework fails

to appreciate.

Responsiveness framework has been criticized further for failing to meet fair sharing of benefits and risks. Grady (2006) for instance notes that, under this guideline, some research applications may be deterred from being conducted in a particular community that the research outcomes may not be relevant to the entire community then, but might be responsive to another community not at the time of the research, but in the future. Most clinical trials and health research usually are of benefit to future generations. Millum (2012), also challenges the ‘reasonably available’ clause in the CIOMS responsiveness claim. He asserts that, ‘the reasonable’ is not clear on whether it refers to monetary value with regard to the product produced albeit a blanket of benefits that the populace may have enjoyed. Alluding to the cost implication, long term goals and uncertain chances of sustainability practically challenge the clause.

It is also evident that responsiveness guideline emphasizes more on the community participating in research, based on their low economic standing and susceptibility to exploitation. Such an outlook fails to delve into benefits holistically. The foreign and resident researchers as well as targeted communities/populations live in different circumstances, meaning that their valuing systems would be totally different, and hence plural values. Thus, for ethical review committees to hold on to responsiveness guideline in permitting a research would be challenged, since it might reject proposals that are ethical probably in the near future. Establishing interrelations and common values in collaborations, amidst plurality of values that define human persons, is pertinent in the responsiveness framework.

2.2 Fair Benefits Framework

The Fair Benefits Framework was proposed and documented by Participants, in a conference held in 2001, on the Ethical Aspects of Research in Developing Countries (Participants, 2002). The framework is guided by the ethical concept of corporate social responsibility. While acknowledging the positivity of collaborative research, the framework argues that communities within which the research project is conducted and the research participants drawn from, those communities/localities should receive fair level of benefit with regard to the contributions they make to the research project.

Fair benefits framework is premised on four background principles. They include social value in research; fair selection of research subjects; the research must have a favorable risk-benefit ratio; and transparency (Participants in the 2001 Conference on Ethical Aspects of Research in Developing Countries, 2002). Along with the principles, several benchmarks were set, for purposes of guiding the research ethical committees on clearing research requests. Among the benchmarks, it is paramount that both the research participants and the entire population enjoy benefits and health improvement during the time of the research (Ibid). Research benefits should also be enjoyed even after conducting the research, a fact that would give room to sort the risks incurred during the course of the research. This framework specifies that host researchers, research participants and their communities should receive a fair level of benefits with the sponsoring researchers.

Laudable for its contextual consideration, but it fails to capture the fact that power imbalances and inequalities exist not only between the researchers from north and those from south, but also between local researchers and the participants. For instance, the imbalance existing between the local researchers and the community in terms of intellectual prowess. Scholars continue to challenge the fair benefit framework. David Wendler and Seemar Shar in their article entitled ‘Fair Benefits and its Critics: Who is Right? (2017)’, document a number of criticisms directed to the framework. Overall, they note that there is no agreement in the ethical literature on what should count as a ‘benefit’ and a ‘risk’ to research participants and their communities in low income settings. In collaborations between low resource and high resource countries, ambiguity looms on what ‘benefits’ entail, given people’s valuing systems. The concepts ushers ethicists into a deliberative and reflective attitudes on not only the terms used in these guidelines but also what counts as a value/ benefit.

With regard to community benefit, the clause ‘social value’ is utterly problematic. CIOMS (2015) guideline 1, defines social value as ‘the importance of the information that a study is likely to produce.’ This points to the claim that, the ethical justification of health related research involving human persons is its social value. Meaning that, the prospect of generating the knowledge and/or the means necessary to protect and promote people’s health takes precedence (CIOMS, 2015). The guiding concept of social value holds predictions that the clinical trials should be such that it yields fruitful results for the good of the community, even before it is undertaken. The alluded positive projections can however, be regarded as exploitive to the recipients, in case they are not met. Further, it is not given that the host community value the knowledge generated from the research. The socially valuable knowledge constructed as a benefit to the host community, further ignores the needs and wants of the said community. It follows that, what the host researchers might gauge as valuable for their communities might be different from what the locals classify as valuable, hence a conflict on what a benefit, is agreed to be.

The future oriented characteristic of fair benefit framework conceptualization of benefits provision has been criticized. Wenner (2018) argues that the framework is a post-trial access which can be exploitative. There is no guarantee that what appears to be a benefit theoretically (in research proposal requests) will be practically achieved.

Shapiro and Meslin (2001), claim that the ethical obligation to provide a health intervention to others in the community, who might benefit from it, is considerably less strong. A laid down plan on how to achieve that, would however, be beneficial because it would help reduce the risk of exploitation. Without a prior and fixed formula of determining how a corporation would attain fair benefits and minimize risks/ manage fair risks, destabilizes the Fair Benefit Framework as viable in its own endeavor. A consideration and early engagement with the host community and low resource researcher prior to commencement and clearance of research requests, would be helpful in analyzing the values of the community members and their researchers. Otherwise imposing research on a community based on virtual benefits is domineering, hence unethical. Worth noting is that both frameworks, that is, responsiveness and fair-benefits are guidelines made by the northerners for adoption by all partners, including the southerners, which poses a context and positionality challenge. In order to evade such a challenge, grounded and local institutional review boards are crucial in scrutinizing research proposals so as to ensure the risks/benefits/justice are upheld in the local communities. The diversities of culture, traditions and ethnicity evident in Africa attunes its ethics to be context oriented, pluralistic and communal. Since as Chukwunke et al (2014) note, ‘communal living, respect for life, respect for personhood, solidarity and justice are the hallmark of African bioethics –common morality not individual morality.’

3. Advances towards a viable framework of benefit sharing in collaborative research

Search for new knowledge and ideologies for guiding both international and national ethical bodies is coming up with considerable frameworks of sharing benefits in collaborative research is an ongoing endeavor. The disparities that accompany collaborative researchers are many and varied. They could be scientific, philanthropic and ethically obligatory in preservation of the intrinsic value of human life. Well-being and health is a fundamental human right that ought to be pursued by all regardless of geographical boundaries and/ economic standing. It is therefore, justifiable that search for new knowledge and parameters of consideration is pursued to enhance collaborative research without exploitation or attitudes of it.

In this spirit, Mcmillan (2010) proposed a rights based approach where researchers from high and low resource countries could be construed as having a duty towards research participants in low resource settings. Such a proposal is laudable, though it poses challenges among ethicists. Drawing legal components into health research has been factored, but a challenge looms if the research is purely philanthropic. Macklin (2004) argues that, if justice as fairness requires that research participants and researchers from low resource setting ought to be treated the same as those from high income setting, it plainly creates a double-standard which is difficult to defend ethically. With the disparities already evident in collaborative research (rich vs.poor), it is difficult to draw ‘potentially beneficial outcomes’ of research that count also as ‘determinants of equity (Macklin, 2012:214).’

Ballantyne (2010) also proposed a global tax framework that he argued would be imposed on international research, with the aim of redistributing research benefits to the least advantaged members of host research countries/communities. Resnik (2010) immediately shot the proposal, with an argument that it is still not ethically clear why only the pharmaceutical industry has been singled out for global taxation, while other re-known laboratories impact the globe with untaxed vaccines. Further, it is unclear how the tax rate could be determined and agreed upon and by whom (Caals and Ho, 2013). In agreement, it is difficult to think of an effective mechanism to collect the tax revenue and even to determine who distributes the tax collected and in what form, without disturbing global peace. Global tax proposal is hence, practically impossible with regard to sharing research benefits in collaborative research. Besides, benefits and risks are not just pegged purely on monetary forms.

The social nature of human persons offers a foundational point of departure in supplementing the frameworks that are already in place. The concept of social justice as outlined in distributive justice is paramount. Some societal values have a universal status of acceptability across all nations, even though some are particular to a specific cultural, geographic, religious or other contexts. Some goods like food, shelter, health, education, security, rights and liberties among others are valued internationally. There is a need to appreciate diversity and differing valuing processes on what passes as a value and of value within our specific environments in spite of common aspirations. In this endeavor, consideration and appreciation of the being of multiple values in differing localities engaged in during health research is vital. Value Pluralism as advanced by Isaiah Berlin is applauded for providing a knowledge component that respects diverging contexts and positionalities evidenced in research partnerships.

4. Value Pluralism

Value pluralism, also known as ethical or moral pluralism, is a moral theory advanced by Isaiah Berlin. He argues that there exists a diversity/plurality of goods, traditions, value systems, ideals, cultures and ways of life amongst human persons. Berlin holds that these values are often incommensurable and irreconcilable, and adamantly irreducible (Berlin, 2005). His arguments flows from conceptualization of diversity of human persons drawn from differing cultures and traditions. As a historian and a philosopher, he based his arguments on reason, noting that human beings are free, rich and diverse beings making ethical decisions on and in this world (Ibid). He asserts,

...[Human] beings, as we know because we ourselves are human, are not merely bodies in space,

moving and being moved but have purposes and motives and act as they do under the influence of other than purely physical or biological causes (Berlin, 2014:266).

Cultural norms and interactions condition human persons to behave and value things differently. Their behavior founds the personalities that human persons exhibit, and are not detached from their being. It is the diversity of these personalities that as Berlin argues, helps human societies identify human worth in all human beings, it actually reflects the essence of human beings (Berlin, 2014).

The contexts within which human persons live and find themselves is as diverse as their values. The global north rich partners have their values so do the south- low resource countries. These values that are always in 'perpetual rivalry' (Berlin, 2002:216). The conflict of values comes about as a result of upholding and respecting the freedom of the individual in valuing, within a distinctive phenomenon. Berlin as cited by Spicer (2010:19), expounds on the conflict.

...Some of the ultimate values by which men live cannot be reconciled or combined, not just for practical reasons, but in principle, conceptually. Nobody can be both a careful planner and at the same time, wholly spontaneous. You cannot combine full liberty with full equality, full liberty for the wolves cannot be combined with full liberty for the sheep. Justice and mercy, knowledge and happiness can collide.

In such instances, then contextual practical reasoning takes precedence with the end/common goal in mind. Living out our lives within differing cultures, we are often molded differently from each other and our human ends are hence many and varied. Given our contexts, it would then be difficult to rank values. Procedurally, one recognizes that some values are sacrificed for the sake of other values. What counts as a value is beneficial and contributes to the wellbeing of the moral subject. HUGO's (2000) statement on benefit sharing captures the concept of valued benefits. HUGO ethics committee states, that 'determining a benefit depends on needs, values, priorities and cultural expectations.' Benefits are thus valued by human persons with regard to their prioritized needs and cultural expectations. Value pluralism appreciates the fact that human person's life is compounded by plurality of values, and what one chooses in one instance and in a particular context, cannot be unified under a single principle, as the formula to a particular value, benefit or good. Benefits are thus, subjectively and inherently value-laden. They are beneficial not of themselves but of course because they are valued as such, accepted by specific person or persons in a given context and event. Thus, a general benefit-for-all is essentially value-based, as it values giving the benefit to all either now or in the future and not only to the needy or to the sick.

With regard to sharing of benefits in collaborative research, where inequalities may lead to exploitation, value pluralism concept in advancing the ethical principles of fairness and autonomy is a component of consideration in this relationship. It brings about an understanding of both partners having differing values as shaped by their cultures and traditions. This heterogeneity is brought along into collaborations, and ought to be appreciated if fairness is to be attained. What is of value and hence beneficial to a researcher from low resource country may not be of value to a researcher from high income country, even though they collaborate in one health research/clinical trial. There are however, mutual and universal values that cut across in humanity, such as health, well-being, responsibility, honesty and hard-work.

While well-being and enhancement of health provision may be the highest value/benefit in sponsoring research in a low income country, the researchers from high resource countries may be driven to the low income country by similar or different values, such as monetary gain and or philanthropism. Whereas, their counterpart in low resource countries may perceive the research to be responsive and of value since it offers them an opportunity for academic publication and generation of new knowledge, a value that is shared also by researchers from the North. This is not to indicate that the sole value of wellbeing and health is transverse, but the drive towards it, is necessitated by other subjective and pertinent values to the actors.

Berlin's value pluralism appreciates that human beings have common fundamental universal categories of valuing, in spite of their differences in culture, religion, country and race. These universal categories enable pursuance of mutual grounds and relationships. The act of valuing what is beneficial and worth pursuing is an essential expression of an individual, which is of essence to one's inherent nature. Berlin is often criticized for fronting subjective valuing (Crowder, 2002), but in defense, he notes that multiple values are objective, which exposes 'the essence of humanity, rather than arbitrary creations of men's subjective' fantasies (Berlin, 2000a:12). Regardless of value conflicts, human beings have an ability of reaching mutual compromise, by understanding that human ends are many, hence in need of mutually agreeable departure towards a common goal in situations that warrant such.

In spite of our differences, our humanness admits sociability that is not reducible due to human persons' inherent dignity. The fairness based on mutual compromise that this conceptualization promises is groundbreaking for successful partnerships. Since as Berlin (2004) suggests, it is better to tolerate and understand other person's values and valuing systems rather than imposing any authoritative power imbalance components that emanate from the evident resource inequalities between collaborating partners. In agreement with Nderitu and Kamaara (2020:9), collaborations are practically and convincingly a 'friendship among unequal parties.' They argue that 'each of the parties receives what is commensurate to their status in an unequal friendship; gain (material benefit)

for the “inferior” party and honour for the “superior” party (Ibid). However, with mutual compromise embraced by the partners, universal ends can be pursued with success, hence shelving the power imbalances depicted. This shows the importance of appreciating pluralism and diversity of benefits and values as fronted in value pluralism. It further, appreciates the fact that, differences and independent values can be abandoned to give way for a mutual universal value, such as health and well-being.

Berlin (1999:137), illuminates the diversity with an argument of ‘identity in difference.’ He argues that pluralistic ends are human expressions that need the freedom of human beings to live as human persons, who make choices and act on the choices. ‘Identity in difference’ thus allows for value diversity and change. This does not mean that one has to buy into the other person’s views, which might lead to exploitation, but should have respect for them as a moral priority or benefit for them. Moral pluralism calls on us to appreciate the incommensurability of moral benefits to an understanding that regardless of moral conflicts, human beings can reach a compromise of the ultimate benefit for each party.

The concept of identity in difference opens to a heterogeneous persona that blends and thrives in difference. Heterogeneous identity is formed when groups of people with differing traits co-exist within a complex, diverse and multi-cultural environment. The recognition and subsequent appreciation of unequal relationships that are characteristic of collaborative research ushers us into an identity that thrives in this diversity.

Value pluralism is enticing as a point of consideration in drawing guiding frameworks of benefit and burden sharing in collaborative research. It positively responds to disparities that deter successful partnerships by admitting plurality of irreducible and potentially conflicting values emanating from the partners contexts and positions; value pluralism as a moral theory admits to existence of diverse goods, traditions, ideals and cultures; and it also appreciates the fact that values/benefits are incommensurable and irreconcilable to one another. Internalization of this perspective would be of importance to international bodies that formulate guidelines on fair sharing of benefits and burdens in partnered research. Collaborations need to be contextualized and adapted to interrelationships operations and values that are necessary for enhancing well-being and successful research partnerships, where burdens and benefits are shared fairly. In agreement Larkan et al (2016:7) points to values as a core concept that is built on commitment, trust, culture and societal norms...’ In order to build on the values of trust and commitment, a prior feasibility socialization between the researchers and the targeted community ought to be planned for and executed. In these meetings, community administrators or spokes persons and representatives (gatekeepers) from the donor partners can agree on mutually universal values, benefits and modes of navigating risks before the research takes place.

Improving well-being and health for all human persons is a universal and fundamental right that should transcend our differences. Listening to each other’s concerns before undertaking a research is fundamental in walking together. Embracing a communal ethic is not founded entirely on oneness, but on a shared value that we all embrace. Listening and understanding the strength of our plurality in its entirety, is foundational and a practical knowledge, worthy of consideration in formulating frameworks of sharing benefits in collaborative research.

5. Conclusion

Fair sharing of benefits and burdens in international collaborative research is key in promoting benefits, respect and justice whilst deterring exploitation. International ethical bodies have fronted guidelines and principles towards this endeavor. Responsiveness debate and fair benefit framework have been fronted as guidelines for sharing of benefits and burdens, though they are constructed in the north and are expected to meet the southern expectations, which is in itself a detriment. The endeavor for an all-round framework that appreciates justice and autonomy is paramount in collaborative research. Rights-based framework and global taxation proposals have been suggested, falling short in criterion of application. This paper has advocated for consideration of value pluralism as a parameter informing benefit and burden sharing frameworks in collaborative research. Value pluralism appreciates diversity in valuing systems within unequal relations as found in collaborative research. The strength of our differences creates a heterogeneous identity that necessitates appreciation of plurality of our values towards an ultimate value mutually and universally binding – health and well-being. Thus any framework viable for sharing benefits and burdens with fairness, while respecting our autonomy, ought to appreciate that collaborations are marred with differing inequalities, and should thus expect differing values. Shared benefits and burdens are thus dependent on what is of value to the subjects concerned, since human ends cannot be unified under a single principle, but can mutually compromise objectively for a universal value. Indeed, collaborative research can be enriched by heterogeneous identity appreciated in value pluralism.

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