

# The social value of research: interrogating the paradoxes

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## Benefit versus value

The relation between science and society is, simply put, very complex. In the history of global bioethics, it is the Code of Nuremberg which foregrounded the acute ways in which biomedical/scientific research could (negatively) impact society; this 1947 Code became the point of reference for subsequent research concerning humans. The Code “required that medical experiments on human beings must have the potential to yield fruitful results for the good of society” (1: p72). The Declaration of Helsinki (DoH), 1964 reinstated this concern by stressing that “clinical research cannot be legitimately carried out unless the risks to participants are justified by the importance of the research” (1) – invoking the idea of the “social value” of research. However, in these initial days, “social value” of research was interpreted more in terms of the moral balance of research, a balance to ensure that the benefits of research unambiguously outweighed its risks as far as its participants were concerned.

According to the Council of International Organisations of Medical Sciences (CIOMS), 2016 (2), “there must be sufficient social value to justify risks to participants in studies that lack the prospect of potential individual benefit to them”. The ICMR Ethical Guidelines for Biomedical and Health Research Involving Human Participants, 2017, state that “The basic requirement for health research to be ethically permissible is that it must have anticipated social value. The outcome of the research should be relevant to the health problems of society” (3: p38). Emanuel et al (4) in their oft-cited paper, argue that, “To be ethical, clinical research must be valuable” (4: p 2703), while Barsdorf and Millum (5) argue that, “The social value of health research should be conceptualized as a function of both the expected benefits of the research project and the priority that the beneficiaries deserve.” (5: p106).

The common thread in these articulations is the idea that “benefits” to participants/community (where research is conducted) should exceed the risks they undergo, implying that this “excess” would be tantamount to the value of research. However, it may be posited that such a paradigm interprets “social value” in terms of *justification* – the risks to participants/community should be justified, the risks should be balanced by the benefits. However, social value should certainly not be seen as “leftover-benefits”. Such a conceptualisation would derogate the idea of value, besides focusing only on the affected/concerned research participants and not on the larger global community. It is important to assert that while benefit must accrue to the research participants, social value should be a broader and more inclusive concept.

## Between ex-ante and ex-post: locating value

While it is the responsibility of the Ethics Committees – besides the researchers themselves – to ensure that a proposed research is of significant value, how do we decide at what point the value should become accessible to the people? Ganguli-Mitra et al (6) describe SVR as a teleological device; however, because a telos is available and usable at the *end* of a process, to relegate SVR to the end of the study does seem to defeat its *raison d'être*; especially when biomedical studies could well take several years to develop and reach completion. Social value should not be quantified as an end product, but as on-going (during research), and extending beyond the time and space boundaries of the said research.

When being envisioned at the start of the research, SVR becomes an *ex ante* concept. When it is evaluated for its effectiveness it becomes *ex post*. Wertheimer is skeptical about SVR, and he argues that there would always be a gap between SVR as *ex ante* and *ex post*. This is because the “reality” of society – which is expected to receive the value – is at a temporal distance. When the research is being carried out – and especially if it is ongoing for years together – the social reality would change significantly and the social value would accordingly shift – it could well become redundant too (7). It is interesting to note that this rhetoric focuses on how best to evaluate value itself; caught between the *ex-ante* conceptualisation of value and its *ex post* evaluation, we debate over the “value of value”.

## Social value for whom?

Even if we advocate for SVR, several questions need to be answered: How should we quantify “value”? How about researches with negative results? For whom should the value accrue? Who constitutes society? Is society always a collective of people or do we also need to attend to the individual? Broadly speaking, there could be three categories of the “social” when we talk of SVR, viz (i) the research subjects themselves, (ii) the community hosting the research extending to the region or the country, and (iii) human population in a more general and global sense, including posterity.<sup>ii</sup>

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If we have to prioritise among these, it seems logical to focus on (i) and (ii), though Nayak and Shah argue (8) that considering a geographical perimeter while evaluating the benefits of a research is unethical. They emphasise the need to ensure that the research offers maximum social value to the globally worst off. This concept of the “worst off” is complex to say the least: What are the coordinates for deciding the degree of being “worst off”? Is it economic? Are the worst off the economically disadvantaged? Or those in a politically tumultuous situation? Or those suffering from intergenerational deprivation and injustice? Or varying combinations of these? Is “worst off” always the label for a collective under which the individual gets subsumed?

The ‘Total Advantage View’ of Sharp and Millum (5) states that “The worst off are those who have the least overall lifetime well-being.” This definition implies that people who die young count among the worst off. So, they say, U-5 children in low and middle-income countries (LMIC) would be among the globally worst off. However, can we afford to have all researches focusing on the worst off populations only? What of the health needs of, for instance, the middle-aged population in Western Europe? This cohort is neither geriatric nor adolescent, not part of LMIC and not marked by other mainstream determinants of poverty or vulnerability. So would this disqualify the cohort from being part of a health study? Would not a systematic denial of research to these relatively better off cohorts also be unethical, if only in the long term? Certainly “worst off” cannot be a location with fixed determinants; it has to be a spectrum where much scope is written in for shifting dynamics and social contingencies.

Against this backdrop, Barsdorf and Millum offer a fresh perspective (5): they argue that prioritising the worst off cannot be a sufficient ethical condition because this would “contribute to further fragmentation of non-disease specific forms of research, such as health systems research” (5: p108). They advocate that we should account for the “magnitude and cause of disease burden and type of research” when focusing on SVR; there is, they argue, more social value in focusing on the *worse off*, instead of the worst off (5: p108). In this frame, social value correlates with the bioethics principle of beneficence; if the research “does good” to the community/society (particularly if the good extends beyond the research participants and accrues to the larger society), it could be perceived as having added value. But when we deliberate on who should be the most prioritised beneficiary of this value, it is the principle of justice that should come into play. It is only by critically using the justice framework that we can arrive at the axes for deciding which community should benefit more from a research, and how. In other words, the social value should be justifiable.

### **SVR of non-biomedical health research**

Discussions on SVR overwhelmingly focus on biomedical/clinical health research. While some ethicists have pointed out this limitation (7: p301), no substantial discussion on health research outside the frame of biomedicine has taken place. One wonders if this glaring lack is because biomedical research is prioritised over social science research, or because it is somewhere assumed that social science research would, by default, have social value. Let us look at a few studies from the social sciences, which have explored specific aspects of health.

I was part of a three-year study (9) which used qualitative methods to understand, among other things, what qualities and characteristics obstetricians considered to be of prime importance in their daily practice of providing obstetric care and service. An overwhelming percentage of the close to 70 respondents said it was communication with the patients (9). Bowser and Hill did a landscape analysis to document “disrespect and abuse in facility-based childbirth” (10: p2010) and came up with a seven-category analytic model of perceived disrespect of women during childbirth. Consider Golombok and Badger’s famous longitudinal study (11) on the emotional health of children versus the different forms of parenting they undergo; the study showed that children of same sex parents display a higher emotional maturity compared to children of heteronormative parents. Finally, Humphreys’ Tearoom Trade study, an ethnographic study of male homosexual behaviour in public toilets. studied how men, even those who did not identify themselves as “gay”, developed their own pattern of sending and responding to signals – body language hand gestures – to set up contingent and fleeting erotic exchanges (12).

Value comes in in a different way in health research within the social sciences – there are no drugs to be developed, no new treatment protocols to be founded. Bowser and Hill’s study revealed how complex the notion of “abuse” is, and helped render abuse a categorical, identifiable, articulable aspect of facility-based maternity experiences; to identify violence and abuse is the first step towards addressing them – and is socially valuable. Social science health research focuses on health in holistic terms, extending to well-being.

Golombok and Badger focus on emotional health and massively subvert existing norms about the “ideal” family type through a meticulous follow-up over close to two decades to demonstrate that the emotional health of children depends not on the gender identity of their parents or their socio-legal relationship, but on a completely different set of factors. The aforementioned study I was part of (9) focused on the quality of obstetric practice in the public and private hospitals of Maharashtra. Identifying that most practitioners valued communication and also expressed that they did not often know the art of communicating well, we, in a follow-up project, collaborated with a medical teaching college to introduce medical humanities in the undergraduate medical syllabus. The value of this study would become even more palpable when more medical students learned to appreciate the need for good communication skills and the doctor-patient relationship would significantly improve over time.

Humphreys' study was severely criticised for having violated the confidence of his participants who had no clue that he was studying them and who took him to be "one of them". He intentionally mis-identified himself and tracked his respondents for follow-up questioning. But it needs to be acknowledged, nonetheless, that he did break some ground by unpacking critical nuances of same-sex relations, especially at a time when it was a major taboo in the US of the 1960s. Humphreys' findings did manage to persuade the police that same-sex encounters were harmless and posed no major threat to society – an important "value" one would say, at a time when homosexuality was considered a criminal offence and suspects indiscriminately rounded up for being "a threat to society".

### Health research: social value and scientific value

The SVR for non-biomedical, qualitative studies shows up along a different set of parameters and could well escape being measured in the same way we measure the SVR of biomedical studies. It needs to be realised that health research is a very broad domain and the questions and methodology locate studies within either the biomedical or the social science paradigm, or at the point of their overlap.

It is important to invoke the concept of scientific value of research at this point. Though the DoH lays emphasis on scientific validity more than on scientific value, both should be considered in conjunction – for one without the other would not yield a healthy study. For the CIOMS, scientific and social value work together to justify the ethical validity of the research. Gopichandran identifies scientific value/validity as the "threshold element of ethics of a research study" (13).

It would be interesting to delineate social value, ethical validity and scientific value-validity in order to interrogate health research in particular. While social value and ethical validity tend to overlap, they are not quite the same: a study – such as Humphreys' – could well yield social value for one or more of the types of the "social" identified above, but nonetheless fall short on ethical standards, as it did, in fact. A sound hypothesis, appropriate methodology, minimised bias, good sampling, data collection, analysis, and so on, contribute to the scientific validity of a study; when the study "proposes a novel hypothesis, the expected outcomes are appropriate to the stated purpose and are useful and if it is feasible to carry out the study successfully in a reasonable period" (13), it is said to have scientific value.

However, neither social value, nor scientific value-validity can exist in isolation, if our aim is to ensure ethical validity. And that should indeed be our aim. Ethics could be erased unintentionally, in the excitement over the attainment of scientific value and social value – and it is incumbent upon the researcher to remain alert to these shifts and possible slippages. Both biomedical and non-biomedical health research are dynamic and transformative, and several of the parameters mutate and change during the lifecycle of the research. Only by remaining alive to these realities can we ensure that research becomes both valuable and ethical.

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### Notes

- <sup>i</sup> Ganguli-Mitra et al. (5) explain social value as a tripartite concept: SVR is a teleological device, a threshold device and a protective device.
- <sup>ii</sup> We could add a fourth "social", viz. the community of researchers themselves to whom the SVR should accrue. However, interrogating the location of this fourth community within the larger social is very complex, not least because this community is also the one designing, conducting and evaluating the value for the other three communities. Keeping this complexity in mind, this article does not focus on it.

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