**SOCIAL VALUE OF RESEARCH:**

**Interrogating the paradoxes**

Rakhi Ghoshal | Asst. Prof. School of Law, AURO University, Surat | [rakhi.ghoshal@gmail.com](mailto:rakhi.ghoshal@gmail.com)

***Science and the social***

The relation between science and society is, simply put, very complex. Seekers of knowledge in ancient times did not make a distinction between questions that concerned nature, the human body and society. In 1959 C. P. Snow in *The Two Cultures and the Scientific Revolution* polemically argued that society had become biased in favour of humanities/social sciences and had come to marginalize the natural/medical sciences. While that opened up a barrage of counter-arguments, we have grown up in a culture where Snow is proven to be 180-degrees in the wrong.

The archetype of the (natural/medical) scientist is a pure one – he[[1]](#footnote-1) asks radical questions, conducts experiments and is not troubled by consequences. He is driven by sheer curiosity (1). Sarukkai talks about the dichotomy between science and the social: advocates of science argue that the task of the scientist is to research, innovate, in short, to find answers: *how* those ‘answers’ would be applicable to the world outside his laboratory cannot be his concern (1). Science – the knowledge and the research was, until recently, believed to be beyond all material, political and social considerations. Society could accept or reject the results of research – and rejection did befall scientists such as Galileo and Darwin – but at the end of the day, concerns of the social did not intrude the onward movement of the behemoth of scientific research. The scientist was a seeker and producer of knowledge, not a user of the same. And thus, Mr. Hyde had to be separated out of the noble personality of Dr. Jekyll, for even in fiction, we could not allow the persona of the scientist to get contaminated.

Historically speaking, one of the most significant moments when this romanticism surrounding the curiosity-filled innocent and essentially harmless scientist was rattled was when the horrors of the Nazi human experimentations emerged: amputations without anaesthesia, people frozen in sub-zero temperatures, flesh burnt off skin and a range of other experimentations, all in the name of the holy trinity of curiosity, science and knowledge. There were other unholy trinities such as power, xenophobia and sadism but for now, we focus on those that invoke science. Following the trials that exposed the details of these human experimentations, the Nuremberg Code was published in 1947. This 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” (2, p72).

The Declaration of Helsinki (DoH, 1964) reinstated this mandate, stating that “clinical research cannot be legitimately carried out unless the risks to participants are justified by the importance of the research” (2). The ‘importance’ of the research is evidently its social value. However, the DoH seemed to imply that social value is a justificatory condition; in other words, if a study poses little or no risk, it legitimately remain devoid of social value. Social value, in this scheme, then becomes a mere moral balance.

***Benefit and value: an incomplete story***

The importance of social value however continued to percolate the scientific consciousness across the globe and the advancement of the bioethics movement played a fundamental role in giving direction to the quest. However, the idea of social value remained hooked up with notions of compensation and risk-benefit.

According to the CIOMS (2016), “there must be sufficient social value to justify risks to participants in studies that lack the prospect of potential individual benefit to them” (p1-2). The ICMR Ethical Guidelines for Biomedical and Health Research Involving Human Participants (2017) states 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” (p38). Emanuel et al. (3) in their oft-cited paper, argue that, “To be ethical, clinical research must be valuable” (p2703), while Barsdorf and Millum (4) 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.” (106).

Notwithstanding the plurality of definitions, the common thread in these 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 reads ‘social value’ in terms of *justification* – are the risks to participants/community justifiable, can the risks be balanced by the benefits? If the benefits seems quantifiably in excess of the risks, would then the ‘excess’ become the placeholder for ‘social value’? One would think that social value should not be the same as ‘leftover-benefit’ for the participants: not only would this derogate the idea of value but also extend to only the participants and not to the larger community outside.

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

Yet another consideration is the ‘when’ – when should the researchers focus on SVR? The common understanding is that SVR should be built into the structure of research, and it is the responsibility of the REC to evaluate the ‘quality of the value’ before the research begins. While it is the onus of the REC – besides of the researchers themselves – to ensure value of the proposed research, at what point should the value become accessible, as it were? Ganguli-Mitra et al. (5) describe SVR as a teleological device[[2]](#footnote-2); 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 some studies in biomedical health take several years to unfold and reach completion. Social value should accrue not just at the end; it needs to exist all through the duration of the research and also exceed it certainly temporally and preferably spatially too.

When being considered at the start of the research, SVR becomes an *ex ante* concept. When it is evaluated for its effectiveness it becomes *post ante*. Wertheimer is skeptical about SVR, and he argues that there would always be a gap between SVR as *ex-ante* and *post-ante*. This is because the ‘reality’ of society – which is expected to receive the value – is at a temporal distance. When the research is going on, and especially if it is going on for years together, the social reality would change significantly and the effectiveness of the value would accordingly shift – it could well become redundant too (6). It is interesting to note that this rhetoric focuses on how best to evaluate value itself; caught between *ex-ante* conceptualization of value and its *post-ante* evaluation, we debate over the value of value.

Wertheimer is not a fan of SVR and concludes that if (i) research participants are provided true and full information, (ii) they give their consent for participation with total autonomy, (iii) they are not exploited in anyway, and (iv) the research is privately funded, such researches might well be exempted from having social value. But Wendler and Rid defend the need for social value (7). Components that come into play whilst considering social value include, but are not limited to, the human and natural resources available at hand and to be used, the geographical setting of the research, the funders and their policies and priorities, the objective of the study and the methodology, among others.

Even if we advocate for SVR, several questions need to be answered: how should we quantity ‘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 need to attend to the individual?

***Social value for whom?***

Broadly speaking, there could be three forms of the ‘social’ when we talk of SVR: (i) the research subjects themselves, (ii) the community hosting the research extending to include the region or the country, and (iii) human population in a more general and global sense, including posterity.[[3]](#footnote-3)

If we *have* to prioritize, it seems logical to focus first 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 emphasize on ensuring that the research offers maximum social value to the globally worst off. This concept of the ‘worst off’ however, is both slippery and counter-intuitive in this context. Who would the ‘worst off’ be? What are the coordinates of deciding the degree of being worst off? Is it economic? Are then 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? Can SVR ever focus on the individual?

The ‘Total Advantage View’ of Sharp and Millum (4) state 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 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 children above five years and living in HIC? Or, take for instance, the health needs of the middle-aged population in Western Europe? This cohort is neither geriatric nor children, the region is not part of LMIC and thus not marked by the mainstream determinants of poverty. Would not a systematic denial of research to these relatively better off cohorts also be unethical, only if eventually? Certainly ‘worst off’ cannot be a position with fixed determinants; it has to be a spectrum where much scope is written in for the shifting dynamics and social contingencies.

Against this backdrop, Barsdorf and Millum offer a fresh perspective (4): they argue that prioritizing 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” (p108). They advocate that we should take into account “magnitude and cause of disease burden and type of research” (ibid) when focusing on SVR – there is, they argue, more social value in focusing on the *worse* off, instead of the worst. Here social value correlates with the bioethics principle of beneficence; if the research ‘does good’ to the community/society (particularly good that exceeds the immediate 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 prioritized beneficiary of this social value, the principle of justice should come into play: the value should be justified to the society and it is only by critically using the justice frame that we can arrive as deciding what axes to use whilst deciding on which community should benefit more from a said research, and how. The value should be justifiable.

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

Discussions on SVR overwhelming focus on biomedical/clinical health research. While some ethicists have pointed out this limitation (6, p301; 8, p78), no substantial discussion on health research outside the frame of biomedicine has taken place. One wonders if this yawning absence is because biomedical research is prioritized 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 social science studies, which explored specific aspects of health:

I was a part of a three-year study 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). The Harvard School of Public Health 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’s famous longitudinal study (11) on emotional health of children versus the different forms of parenting they undergo; the study showed that children of same sex parents display the highest emotional maturity compared to children of single parents, while children of heteronormative parents score the least on the scale. Finally, Humphrey’s Tearoom Trade study: it is an ethnographic study of male homosexual behaviour in public toilets; Humphrey 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 non-biomedical health research; there are no drugs to be developed and distributed, no new treatment protocols to be founded which can alter existing practice. The Harvard School 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 certainly of much social value. Social science health research focuses on health in holistic terms – more on well-being than just health.

Golombok focuses on emotional health and massively subverts existing norms about the ‘ideal’ family type showing through a painstaking follow-up over close to two decades that emotional health of children depends not on the gender identify of their parents or their socio-legal relationship, but on a completely different set of factors. The study I was part of helped identified the health of obstetric practice per se. Identifying that most practitioners valued communication and also expressed that they did not often know the art of doing it well, we, in a follow-up project, collaborated with a medical teaching college to introduce medical humanities in the undergraduate medical syllabus. Value would become more palpable when more medical students would learn to appreciate the need for good communication skills and the doctor-patient relation would improve over time.

Humphrey’s study was severely criticized 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 nonetheless acknowledged 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 U.S. of 1960s. Humphrey’s findings did manage to persuade the police that same-sex encounters were often times 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 realized that health research is a broad domain and the questions and methodology locate specific studies within either the biomedical or the social science paradigm, or at 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 the scientific value, both should in fact be considered in conjunction – for one without the other would not yield a healthy study itself. Gopichandran identifies scientific value/validity as the “threshold element of ethics of a research study” (13). For the CIOMS, scientific and social value work together to justify the ethical validity of the research, but gives priority to social value if and when the scientific and social come into any conflict.

It would be interesting to delineate social value, ethical validity and scientific value-validity in order to interrogate particularly health research. While social value and ethical validity tend to overlap, they are not quite the same: a study – such as Humphrey’s – could well yield social value for one or more of the ‘socials’ identified above, but nonetheless fall short on the ethical standards, as it did. Setting up a sound hypothesis, appropriate methodology, minimized bias, 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), a study is said to have scientific value.

However, neither social value in a standalone way, nor scientific value-validity in isolation can ensure ethical validity. Ethics could well slip out behind the bonhomie over the attainment of these twin values – and it is incumbent upon the researcher is to remain alert to these shifts and possible slippages. Both biomedical and non-biomedical health research is 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.

\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*

* CoI: None
* Funding: None

***References:***

1. Sarukkai, S. 2009.
2. Rid. Editorial. 2017.
3. Emanuel E.J., Wendler D., Grady, C. 2000. What makes clinical research ethical? JAMA; May 24-30; 283(20): 2701-11.
4. Barsdorf and Millum. 2017.
5. Ganguli-Mitra ET AL. 2017.
6. Wertheimer. 2015.
7. Wendler and Rid. 2017.
8. Nayak and Shah. 2017.
9. Ghoshal et al. 2013.
10. USAID. 2010. Exploring Evidence for Disrespect and Abuse in Facility-Based Childbirth
11. Golombok, S.
12. Humphrey, L.
13. Gopichandran, V. (Forthcoming).

1. The archetypical scientist is invariably a man. [↑](#footnote-ref-1)
2. Ganguli-Mitra et al. (5) explain social value as a tripartite concept: SVR is a teleological device, threshold device and protective device. [↑](#footnote-ref-2)
3. 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. [↑](#footnote-ref-3)