

1 **DOI: <https://doi.org/10.47391/JPMA.1449>**

2  
3 **Research in vulnerable communities, a long journey from**  
4 **vulnerability to empowerment.**

5  
6 **Farah Asif**

7 Shaukat Khanum Memorial Cancer Hospital and Research Center, Lahore, Pakistan

8 **Correspondence:** Farah Asif. **Email:** crc3@skm.org.pk

9  
10 ‘Medical research is only justifiable if there is reasonable likelihood that the  
11 populations in which the research is carried out stand to benefit from the results  
12 of the research’

13 Barira Wahid has updated about epidemic of HIV in a named small geographical  
14 territory in Pakistan and its possible causes, in Lancet is recent issue (1). Writer  
15 has rightly identified discrimination and stigma associated with HIV/AIDS, in the  
16 context of socially conservative setting of Pakistan. Facts described in this write  
17 up reportedly came from PCR-based screening carried out by The Health  
18 Department at District Headquarter Hospital, Sargodha and study involving  
19 interviews of villagers who visited the laboratory. No information is provided if  
20 ethical approval from competent authority was obtained for this research activity.

21 Similar questions arise like: Was the community or representative of the  
22 community aware of this research? were the participants informed about the  
23 expected results and dissemination plan of this study? Were their appropriate  
24 protective measures in place before this vulnerable population can be studied?  
25 did the participants have a chance to review this write up and approved this before  
26 publication? The ones who participated in this research, would they ever get to  
27 know what has been reported about them? Is there any thought about what would

28 be the implications of this research report on the community which is being  
29 studied?

30 Article reports, “A substantial proportion of patients might have acquired the  
31 infection sexually, but they were reluctant in discussing their sexual  
32 relationships”. With no mention of scientific basis and certainty, it is not clear  
33 what has led the authors to make this presumption of a sensitive nature in the  
34 context of the society and prevalent religious beliefs in the region. Legitimacy of  
35 this assumptive statement is questionable.

36 Progressively role of vulnerable populations has assumingly changed from  
37 passive to active, and it is clearly needed. San Code of Research Ethics 2017 (2)  
38 is a unique expression of active role of vulnerable population. It is the first code  
39 of conduct for research to be developed by a vulnerable indigenous group called  
40 San, in Africa. The development of code is rooted in the history witnessing how  
41 San felt abused by researchers. In 2010, publication of genomic research  
42 involving San, (3), was unacceptable to San leadership. It bypassed their councils  
43 which existed and were charged with the role to protect their people from  
44 exploitative research. Trust project, has supported the development of san code,  
45 and Global code of conduct for research in resource poor settings (4). Though it  
46 cannot replace existing guidelines and regulations, it sets out requirements which  
47 will be acceptable to San and other resource poor countries, if researchers would  
48 want to study their population.

49 Do we need more regulations and codes, and if yes, how many of these will be  
50 sufficient. The effectiveness and compliance of all regulations depends on core  
51 values like honesty, integrity and acceptance of legitimacy of proposed  
52 mechanism, which is unfortunately hard to monitor or implement. At the end, all  
53 what is needed is a commitment from researchers, that research in vulnerable  
54 populations should be conducted only if it falls in pre-defined Research priorities  
55 of vulnerable population, ensuring local representation in all stages of research  
56 including development, review and publication. Further any research activity

57 involving vulnerable population should allocate a fair bit of resources to empower  
58 the vulnerable population under study.

59

60 **Disclaimer:** None to declare.

61 **Conflict of Interest:** None to declare.

62 **Funding Sources:** None to declare.

63

#### 64 **References**

65 1. Barira W. *An update on the severe outbreak of HIV in Kot Imrana,*  
66 *Pakistan.* Lancet Infectious Diseases. 2019;19(3): 241

67 2. South African San Institute. *San Code of research ethics.* Available from:

68 [http://passthrough.fw-](http://passthrough.fw-notify.net/download/249657/http://www.globalcodeofconduct.org/wp-content/uploads/2018/04/San-Code-of-RESEARCH-Ethics-Booklet_English.pdf)

69 [notify.net/download/249657/http://www.globalcodeofconduct.org/wp-](http://www.globalcodeofconduct.org/wp-content/uploads/2018/04/San-Code-of-RESEARCH-Ethics-Booklet_English.pdf)

70 [content/uploads/2018/04/San-Code-of-RESEARCH-Ethics-](http://www.globalcodeofconduct.org/wp-content/uploads/2018/04/San-Code-of-RESEARCH-Ethics-Booklet_English.pdf)

71 [Booklet\\_English.pdf](http://www.globalcodeofconduct.org/wp-content/uploads/2018/04/San-Code-of-RESEARCH-Ethics-Booklet_English.pdf) (Accessed on July 23, 2019).

72 3. Schuster SC, Miller W, Ratan A, et al. *Complete Khoisan and Bantu*  
73 *genomes from southern Africa.* Nature. 2010;463(7283):943–947.

74 4. *Global Code of Conduct for research in resource poor setting* (Internet).

75 2018. Available from:

76 [http://ec.europa.eu/research/participants/data/ref/h2020/other/hi/coc\\_research-](http://ec.europa.eu/research/participants/data/ref/h2020/other/hi/coc_research-resource-poor-settings_en.pdf)

77 [resource-poor-settings\\_en.pdf](http://ec.europa.eu/research/participants/data/ref/h2020/other/hi/coc_research-resource-poor-settings_en.pdf) (Accessed on March 7, 2019).

78