



# INDEPTH/COHRED seminar in Nairobi

INDEPTH partnered with COHRED to co-organize a closed seminar in Nairobi in July on sharing public health research data. The seminar honed in on the particular problems and potentials from the point of view of research in low- and middle-income countries: i) the impact of low resources and more limited analytic and data management capacities and facilities, ii) ethical issues generated by open data sharing, and iii) what constitutes a ‘fair trade – not free trade’ in research data between low- and high-income countries? The ultimate aim of this workshop is to build consensus from the perspective of low- and middle- income countries on the practical implications for and responses to sharing public health research data. One expected outcome of this meeting is a draft code of conduct for sharing public health data.

## Research funders urged to be committed to fair trade, not free trade

Story: Rebecca Kiumi, Nairobi 01, Kenyan

THE Executive Director of INDEPTH Network, Anwar, the Ghanaian Sankoh, has called on research funders to be committed to ‘fair trade, not free trade’ with regard to sharing research data by putting in place mutually binding agreements and measures.

This was in response to a statement of support by several research funders on sharing research data to improve public health in an article published on July 30, 2011 in *The Lancet*, titled: ‘Sharing research data to improve public health: a perspective from the global south’.

He said although scientists were willing to share research data to improve public health, it must be done in a way such that researchers in resource-poor settings during much of the week to generate data did not have to be overworked and underpaid in the global South.

“We have to seek the balance between the rights and responsibilities of those who generate data and those who analyse and publish on such using those data”, Dr Sankoh said.

Dr Sankoh made the call at a two-day seminar on ‘Ethics of Sharing Public Health Research Data: Perspectives from Low and Middle Income Countries’ in Nairobi, Kenya from July 28-29, 2011.

The seminar, which was organized by INDEPTH Network and the Council on Health Research for Development (COHRED) and hosted by the African

Population and Health Research Centre (APHRC) was, among others, such solutions on ethics, technical, process, and capacity strengthening issues of sharing public health research data.

More than 15 researchers, demographers and statisticians from various INDEPTH member health research centres in Africa and Asia participated in the seminar.

Dr Sankoh said, it was welcoming news that after a series of meetings from 2008, 17 health research funders had come up with a joint statement to support public health research scientists to share data in ways that were equitable, efficient and ethical.

He said sharing data had many benefits such as a potential to guide policy makers to make informed decisions to improve public health.

What was important, he said, was for scientists in the South to strengthen their capacity so that they would not only generate data but be able to analyse and publish results from those data.

He emphasized that data sharing was not new to INDEPTH Network, scientific and non-scientists had been sharing data with a cross-section of organizations and students.

For his part, Carol L'Abordt, the Director of COHRED, said, resource researchers gave the next sharing data was that it would affect patent confidentiality, excepting a data set for sharing, was too much work and data might be analysed using second methods.

However, he noted that misuse of data was one of the downsides of sharing, but it



Dr Sankoh (left) meeting with Dr Abdoulaye (right) and Dr Margaret Gyapong (left), Director, African Health Research Centre

was a price worth paying.

“If we give priority to the interests of the research funder that a meeting the question of how widely that data should be shared is easy. Patients volunteer for research because they want to benefit others. It is in their interests for the beneficiaries of their contribution to be maximised. Data sharing, rather than data hoarding, achieves this goal,” Dr L'Abordt said.

He said key ethical issues identified for not sharing data, were ‘technical’ and ‘personal

which could be overcome by filling the gaps in data management, resource limitations to clean data and establish data libraries.

A Policy Advisor at the Wellcome Trust, David Carr said the organization was dedicated to ensuring that research outputs were preserved and shared to maximize their long-term value.

He said the trust was committed to supporting high quality health research that was timely and widely used, transparent and available to others and quickly translated into bet-

ter policies and better health.

However, he said the current situation for public health research was that data analysis and reporting were slow and incomplete and also that lack of access to data limited the capacity for comparative analysis or cross checking for accuracy.

Therefore, Mr Carr said it was important to have a reasonable balance that, with enough ethics, ensure the confidentiality of participants in a research, protect organizations of health centres and not both researchers in health.

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[Proceedings of the INDEPTH/COHRED Nairobi Meeting : Ethics of Data Sharing. September 2011](#)



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