

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

Story: **Rebecca Kwei, Nairobi, Kenya**

THE Executive Director of INDEPTH Network, Accra, Dr Osman 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 purpose 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 doing much of the work to generate data did not lose out to better-resourced researchers in the global North.

"We have to seek the balance between the rights and responsibilities of those who generate data and those who analyse and publish results 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 organised by INDEPTH Network and the Council on Health Research for Development (COHRED) and hosted by the African

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

More than 30 researchers, demographers and scientists 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, ethical and efficient.

He said sharing data had many benefits such as 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 emphasised that data sharing was not new to INDEPTH Network, since its various sites had been sharing data with a cross-section of organisations and students.

For his part, Carel IJsselmuiden, the Director of COHRED, said reasons researchers gave for not sharing data was that it would affect patient confidentiality, compiling a data set for sharing was too much work and data might be analysed using invalid methods.

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



• **Dr Sankoh (middle) interacting with Dr IJsselmuiden (right) and Dr Margaret Gyapong (left), Director, Dodowa Health Research Centre.**

was a price worth paying.

"If we give priority to the interests of the research subject then answering the question of how widely their data should be shared is easy. Patients volunteer for research because they want to benefit others. It is in their interests for the usefulness of their

contribution to be maximised. Data sharing, rather than data hoarding, achieves this goal," Dr IJsselmuiden said.

He said key obstacles identified for not sharing data were 'technical' and personal

which could be overcome by filling the gaps in data management, increase incentives to share data and establish data libraries.

A Policy Advisor at the Wellcome Trust, Dave Carr said his organisation was dedicated to ensuring that research outputs were preserved and shared to maximise 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 the lack of access to data limits the capacity for comparative analysis or even checking for accuracy.

Therefore, Mr Carr said it was important to have an ethical balance that will among others ensure the confidentiality of participants in a research, prevent stigmatisation of small communities and better investments in health.