

first day is symptomatic—people will flock to the hospitals and seek care, in many instances assuming that this bout of generosity will soon come to an end.

Finally, it remains unclear why the idea of social health insurance that was once high on the agenda had not been followed up. The current international debate on health-care financing now mainly sees a prudent mix of different sources (tax, social insurance, out-of-pocket, external aid) as the most successful way of financing health.

This is a great initiative from a decisive leader. A journal like *The Lancet*, however, should not get carried away and become overly enthusiastic about an initiative that requires careful and continuous follow-up to avoid a straw fire and bitter disappointment.

I worked in 2008 as a consultant for the International Labour Organization in Sierra Leone on health-care financing for the country.

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1 Donnelly J. How did Sierra Leone provide free health care? *Lancet* 2011; **377**: 1393–96.

### Author's reply

Konrad Obermann's points echo several donors' concerns from a few years back about whether Sierra Leone should even try to offer free health care for pregnant women, breastfeeding mothers, and children younger than 5 years. The argument went: you can't sustain this, so don't even try. Sierra Leone's President, Ernest Bai Koroma, and the country's senior health officials listened to them and went ahead anyway—with a carefully thought-out strategy, involving some of those same donors, to start the construction of a health system that has been very weak. Obermann raises a good point about whether the initiative will be sustainable. The story, though, was about how Sierra Leone pulled this off, against great odds. The story

examined a handful of key moments. Any judgment about sustainability, by definition, won't be available for several years.

As for Obermann's pooh-poohing of the initiative because "a large part of the population will not experience any change at all", that would come as a surprise to many Sierra Leone residents, including men, older children, and older women. I believe they see a great benefit. The initiative will surely improve the health and save the lives of mothers, the lifeblood of society.

I declare that I have no conflicts of interest.

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## Sharing research data to improve public health: a perspective from the global south

Mark Walport and Paul Brest (Feb 12, p 537)<sup>1</sup> wrote on behalf of several research funders about a statement of purpose on sharing research data to improve public health. INDEPTH, a southern-based research network, the Council on Health Research for Development (COHRED), an organisation enabling research and innovation systems for health in low-income and middle-income countries, and many other people are pleased with this demonstration of leadership and commitment. We wish to comment on three areas and suggest a way forward.

First, Walport and Brest state that they are committed to "fair trade, not free trade" when it comes to data sharing. The question is how to achieve fair trade. Fair trade is usually governed by mutually binding agreements and measures. This implies achieving a balance between the rights and responsibilities of those who generate data and those who

analyse and publish results using those data. Such a balance lies in ensuring that the means and capacity to share and actively participate in the analysis of those data are in the hands of those who generate the data and not only in those who want to analyse it.

Second, there is a need to clarify what is meant by "population data collected for health research"; this is not a homogeneous entity. Some data will be substantially more straightforward than others. For example, in the INDEPTH/WHO SAGE multicentre study on ageing, health, and wellbeing in eight countries in Africa and Asia,<sup>2</sup> it was not too difficult to put a single cross-sectional survey datafile into the public domain within a few months of completion of data analysis and publication. Addition of individually linked mortality data from the same contributing longitudinal health and demographic surveillance systems would be much more difficult. Longitudinal surveillance data are more complex and dynamic. We are, however, making good progress in understanding how to deal with such data.

Third, in addition to data analysis capacity, southern-based research institutions typically do not have the legal capacity to ensure that the contracts they sign with international research partners give them a fair share of the benefits from collaborative research. Without this, even contracts negotiated in good faith can lead to inequitable agreements that might not deal with, for example, fair data ownership, technology transfer, capacity building, intellectual property rights, and future benefit sharing.<sup>3</sup>

Walport and Brest state that, "As funders of public health research, we need to ensure that research outputs are used to maximise knowledge and potential health benefits". However, such health benefits seem to be limited to technical solutions to address specific diseases or health conditions, which ignores the fact that most health benefits, particularly in low-income and middle-income



For more on sharing of longitudinal surveillance data see <http://www.indepth-ishare.org/>

countries, result from creating environments, capacities, and systems in which what is already known can be applied.<sup>4</sup>

Further, to be effective, discussions around data sharing must not be limited to individual research projects. The Demographic and Health Surveys programme has a technical Data Processing and Development team that deals with data processing, cleaning, analyses, storage, sharing, and ICT systems. Although it is unlikely that such a system could be easily replicated in every country, funders could identify and invest in specific data systems in the global south, and in stronger academic institutions with regional partnerships, that hold the greatest promise for maximising public health knowledge.

We declare that we have no conflicts of interest.

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## Fifty years of evolution of the term Down's syndrome

In April, 1961, *The Lancet* published a letter to the Editor<sup>1</sup> written by 19 well known geneticists who proposed that the terms mongolian idiocy, mongolism, and mongoloid, with their misleading racial connotations, be

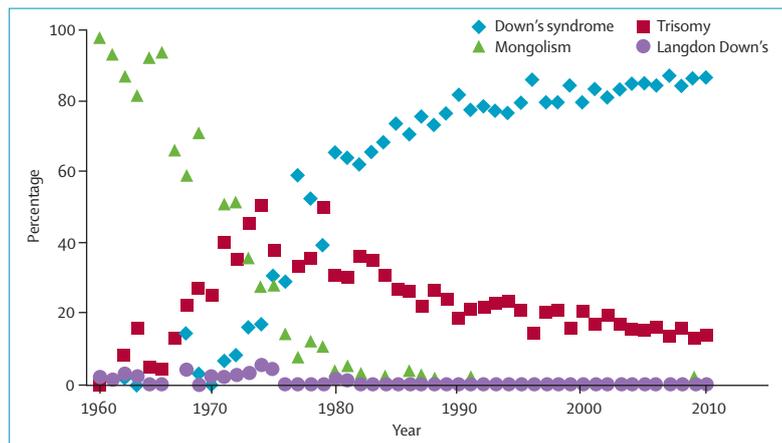


Figure: Evolution of the use of the terms "mongolism", "Down's syndrome", "trisomy 21", and "Langdon Down's syndrome" in publication titles listed in PubMed (1961–2010)

replaced by Langdon-Down anomaly, Down's syndrome anomaly, congenital acromicria, or trisomy 21 anomaly. This letter, reprinted the same year by the *American Journal of Human Genetics*, was decisive in a change that has affected not only the medical vocabulary and the scientific literature but also the way in which the media and laypeople address the disease today.

We investigated the use of the various names given in publications registered in the PubMed database from 1961 to 2010, as a proportion of the total. These data were obtained through a selective search for the different proposed names, without displaying any of the others. The total number of denominations for the syndrome, sometimes also called disease and anomaly, were 5289 for Down, 1396 for trisomy 21, 524 for mongolism, 25 for Langdon Down and four for congenital acromicria. Historical articles were not considered.

As shown in the figure, use of the term "mongolism" diminished progressively and disappeared in the early 1980s, since then only being used in articles concerning the history of the syndrome. "Down's syndrome" is the most widely accepted. "Trisomy 21" is preferentially used when referring to the disorder in association with other chromosomal abnormalities.

Other proposed denominations are not used at present.

In their letter, the authors stated: "It is hoped that agreement on a specific phrase will soon crystallise if once [sic] the term 'mongolism' has been abandoned"—a hope that has been fully realised.

We declare that we have no conflicts of interest.

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## Department of Error

Boussier M-G, Amarenco P, Chamorro A, on behalf of the PERFORM Study Investigators. Terutroban versus aspirin in patients with cerebral ischaemic events (PERFORM): a randomised, double-blind, parallel-group trial. *Lancet* 2011; **377**: 2013–22—The list of PERFORM trial investigators for this Article (June 11, 2011) has been corrected online as of July 29, 2011.

Beaglehole R, Bonita R, Alleyne G, et al, for The Lancet NCD Action Group. UN High-Level Meeting on Non-Communicable Diseases: addressing four questions. *Lancet* 2011; DOI:10.1016/S0140-6736(11)60879-9—In this Health Policy piece (published online June 13), Sania Nishtar's name was spelt incorrectly. This correction has been made to the online version as of July 29, 2011, and to the printed Article.

See [webappendix](#) for the full list of authors

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