

The Chinese Government should design policies to address these issues, improve the insurance system, train rehabilitation therapists, and provide health education for the general population. The experience and technological advances of rehabilitation in Japan could be useful in informing stroke treatment in China.

We declare no competing interests.

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## The dilemmas of the European Union's open access to data policy

European, Arab, and Turkish researchers worked for 2 years on research in six southern and eastern Mediterranean countries, funded by the European Union's (EU's) Seventh

Framework Programme for Research and Technological Development. This project allowed researchers from these countries to explore and analyse their peoples' situation in times of turbulent changes. It also created potential collaboration within various research teams and between researchers and their European counterparts in these six countries.

Open access policies are instrumental in allowing researchers from southern countries access to published research and in decreasing the knowledge gap between north and south. However, this network's experience revealed an unanticipated aspect of the EU policy<sup>1</sup>—ie, it might actually increase the research production gap.

The EU's call for open research data<sup>2</sup> is commendable in principle. In practice, this policy presents problems. Many researchers of southern countries are overworked and have little access to funds to buy time to analyse results and write articles before data is shared by others. When research projects require sharing of these data publicly, partners in better financed institutes (usually those in European countries) have access and opportunity to publish such data before researchers from southern and eastern Mediterranean countries.

Although the EU stipulates that an embargo on making such data public is allowed, tensions related to contexts and institutional arrangements have occurred: some researchers from Europe wanted publicly available data as soon as possible, and some from southern and eastern Mediterranean countries voiced that they could not cope with the narrow embargo times proposed. There were sympathies to issues raised by some from southern and eastern Mediterranean countries other than fundraising to buy writing time—eg, capacity building of young researchers, southerners writing about themselves instead of being written about by others, and contributing to knowledge production corresponding

to their interpretation of their communities. Consequently, there was a compromise to be approved by the EU, in tribute to the network coordinators who ensured these dilemmas were presented to all fairly.

Although researchers everywhere are keen to publish, causing possible institutional pressure to be universally high, a huge production gap of research completed, written, and published by local researchers exists between high-income, middle-income, and low-income countries. The EU-sponsored research projects allow for partnership development, whereby researchers in low-income countries can collect data and generate knowledge through their own writing, either independently or in cooperation with colleagues from high-income or southern countries. It is difficult to imagine that these projects would allow researchers from high-income countries to run with the data and publish before those from low-income and middle-income countries have had the chance to develop their own data analysis. This thought raises the issue of making data publicly available without specifically encouraging or stipulating collaboration with researchers from the countries where the data was gathered. There is also risk to communities involved in such free-to-all data access, not only of possible misinterpretation but a political risk to study participants, depending on what research question is raised, and how data are analysed. Therefore, collaboration between in-country researchers and others who want to use the data once made public is also required.

In the end, an understanding and compromise was made. However, the lessons learned are worthy of further discussion in the EU, because open access policies can have unintended negative consequences. For after all, the basic ethical issue in research is “do no harm”.

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- 2 European Commission. Open research data in horizon 2020. 2016. [http://ec.europa.eu/research/press/2016/pdf/opendata-infograph-ic\\_072016pdf#view=fit&pagemode=none](http://ec.europa.eu/research/press/2016/pdf/opendata-infograph-ic_072016pdf#view=fit&pagemode=none) (accessed Nov 2, 2016).

## Response to what WHO can do to support research in LMICs

José M Belizán and Suellen Miller<sup>1</sup> (April 29, p 1697) described what the WHO could do to support research in low-income and middle-income countries (LMICs) with an emphasis on better use of evidence in policy development. WHO established the Evidence-Informed Policy Network (EVIPNet)<sup>2,3</sup> in 25 LMICs in Africa, Asia, and Latin America with the main goal of bridging the gap between research and policy. EVIPNet teams, composed of researchers, policy makers, and civil society, facilitate access and synthesis of evidence, develop policy options, and organise discussions between stakeholders—in which individuals can speak openly without fear of retribution—to build trust and improve communication. EVIPNet teams involve policy makers at all stages of

the research and policy development process, thus addressing the absence of congruence between the research design and the needs of the study population. These knowledge broker units, which aim to make research understandable to policy makers, are valuable components of the multidisciplinary research centres in LMICs that Belizán and Miller<sup>1</sup> proposed.

Research in LMICs also benefits from improved information about ongoing research, including clinical trials, with more being done in LMICs to address problems such as poor transparency, accountability, and ethical misconduct. WHO acknowledged these problems, and subsequently established the International Clinical Trials Registry Platform (ICTRP),<sup>4</sup> which enables researchers in LMICs to access trials within their own countries and globally. The ICTRP has led to the creation of clinical trial registries in many LMICs and has improved the efficiency of research by facilitating collaboration between researchers and maximising the use of scarce resources and facilities.

WHO needs to continue to be a strong and vocal supporter of research in LMICs and must play a central role in influencing the agenda of major agencies that fund research to direct resources to this important and often neglected area. It is hoped that the new Director-General of WHO will give this matter high priority.

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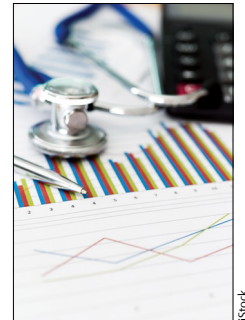
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## Patients' decisions on joint replacement need data on earnings and welfare benefits

The study by Lee Bayliss and colleagues<sup>1</sup> (Feb 13, p 1424) provides useful prognostic evidence of the lifetime risks of joint revision. After hip or knee replacement, the revision rate is 5% for men and women older than 70 years, but as high as 35% for men in their early 50s.<sup>1</sup> But the risk of revision needs to be weighed against the potential gains from remaining in work and continued earnings. Research is needed to help patients decide and in theory, this research is possible in England. It requires use of the National Health Service (NHS) resource, NHS Digital, to enable linkage between NHS data and data on benefits and earnings held by the Department for Work and Pensions and Her Majesty's Revenue and Customs. These government departments need share only identifiers, not the patient's health or earnings records, and researchers would link only de-identified extracts from health, benefits, and earnings records, under strict controls.

In practice, however, such research is unlikely to be allowed in England. Under section 122 of the Care Act 2014, NHS Digital can only disseminate data for the "provision of health care or adult social care or the promotion of health".<sup>2</sup> Interpretation of the Care Act by NHS Digital and the newly established Independent Group advising NHS Digital on the Release of Data (IGARD) is increasingly restrictive, and NHS Digital has opted out of the upcoming Digital Economy Bill, which is expected to allow cross-sectoral linkage of administrative data for research.<sup>3</sup>

Researchers can encourage debate about the potential harms of these restrictions by engaging more directly with NHS Digital, IGARD, and the Health Research Authority to increase



For more on the ICTRP see <http://www.who.int/ictrp/en/>