



Public consultation invited on health databases and biobanks

(09.04.2015) An open consultation on the ethical issues surrounding health databases and biobanks has been announced by the World Medical Association.

Starting today (Thursday) for a two month period, the WMA is inviting comments on its proposed principles for the ethical use of data in health databases and human biological material in biobanks. This follows the successful public consultation procedure adopted two years ago by the WMA when it revised its Declaration of Helsinki.

The WMA is taking this step because of the need for the medical profession to have guidance about how to ethically approach the rapidly growing agendas of health databases and biobanks. It is hoped the final guidance will benefit both the medical and wider research communities, as well as all those affected by such research by avoiding possible abuse or endangering the trust of those whose data is held.

In a joint letter sent out today to national medical associations and interested outsiders, Dr. Jón Snædal, Chair of the WMA's Workgroup on Health Databases and Biobanks, and Dr. Otmar Kloiber, WMA Secretary General, refer to the risks and advantages of health databases and the need for guidance on the way forward.

They write: 'Informed consent, although not perfect, is the strongest instrument for protecting personal autonomy, and with it self-determination and dignity. It is the primary means for all potential research subjects to express their will and/or preferences. We consider it a crucial instrument for protection and respect.

'Research is changing. Large collections of data and human specimens allow for the development of new research strategies and models, as well as new predictive types of research and analysis. The combination of large amounts of data, the possibility of combining large databases and the application of information technology are already changing all aspects of our lives. Research is no exception.

'The potential of such databases is vast, but so are the dangers. While there is a strong possibility of finding solutions, cures and remedies for a multitude of medical

problems, illnesses and suffering, the challenge lies in the high potential for the abuse and misuse of health databases and biobanks. We are convinced that the answer to this dilemma is to be found in an ethically correct process which takes into account the willingness and trust of those donating and sharing their data (or specimens) as well as acknowledging the obligation to apply high standards of protection.

Accompanying the letter are draft guidelines drawn up by a WMA Workgroup, which, say the authors of the letter, amount to a balanced approach by requesting broad consent from the donors of data or specimens indicating their preparedness to share or donate their data or material for later use.

Dr. Snædal, Chair of the Workgroup, said: 'We concluded that the major risk scenarios do not result from science, but from the commercial, administrative or political use of this data. Limiting our guidelines to research only would have left us blind to the imminent risk of abuse from outside the field of medicine, from commercialisation, cost-cutting and potential political abuse.

'So in contrast to the Declaration of Helsinki, this proposed policy aims to address any use of health databases and biobanks and is not restricted to research.'

Public comments on the draft guidelines are invited up until June 5

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