





Sharing and reuse of health-related data for research purposes: WHO policy and implementation guidance



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Foreword

When data related to research activities are shared ethically, equitably and efficiently, there are major gains for science and public health. However, the extent of sharing of health research data sets is lower than is needed to unlock these gains. This is why we are prioritizing the development of practical guidance to assist the many World Health Organization (WHO) colleagues who manage health research to enable greater sharing of research data. WHO staff members may be responsible for research projects funded or sponsored by WHO, or they may be involved in research in other ways – such as by coordinating networks of researchers or providing technical support to ministry of health staff who manage or fund research programmes.

As I write this Foreword we have seen the problems caused by the lack of data-sharing on COVID-19. Many thousands of COVID-19 clinical trials have taken place, but most have been too small or inadequately designed to provide useful evidence for policy-makers. A more mature ecosystem for curating and aggregating data sets would have been extremely helpful in collating the evidence base for decision-making. It is therefore very timely for WHO to publish this guidance which provides practical assistance to our staff in how to ensure that that final data from health research with which WHO is associated are further shared for reuse. WHO believes that the global scientific community should embrace the norm of sharing of data sets at the time of publication and, in some cases (such as pathogen genomic data), even prior to publication.

In parallel, the legitimate equity and career development needs of researchers around the world need to be addressed through initiatives that ensure access to medical products that are developed and to capacity development, including in data management and analysis. WHO's view is that the sharing of health data is a global public good. Countries that share data should be applauded, and never penalized, for contributing to that public good.

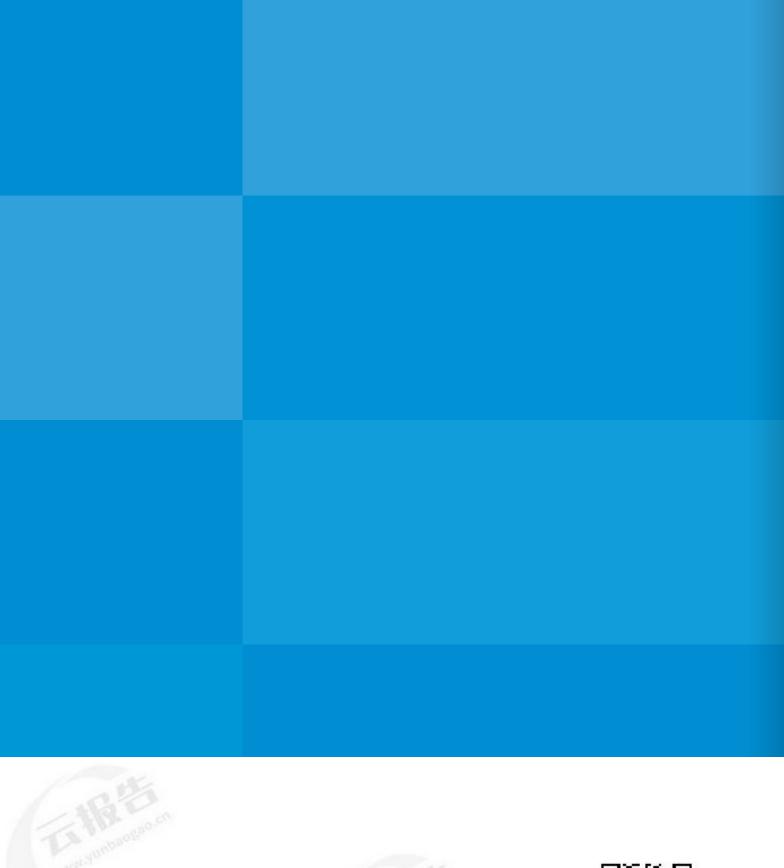
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