The WorldWide Antimalarial Resistance Network’s efforts to “level the playing fields” for data sharing by researchers in malaria endemic countries

Karen Barnes

1University Of Cape Town, South Africa

The Global Health Network

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The WorldWide Antimalarial Resistance Network (WWARN) was established in 2009 to understand and curtail the threat of antimalarial resistance. Key to delivery on WWARN’s aims was engaging with global malaria researchers and convincing them to share their data with the central WWARN repository at a time before data sharing was required by policy makers, funders and publishers. As the real and perceived barriers to data sharing were many and diverse, WWARN developed a number of strategies to enable and encourage ethical and equitable sharing of reliable data to inform malaria treatment policies and practices. This case study will focus on efforts to promote equity in sharing of data by, and with, researchers from malaria-endemic countries.

WWARN is committed to ethical, open and transparent practices which respect the rights of patients/study participants, researchers and organisations contributing to the WWARN Data Repository. WWARN also realizes that there is a danger that better resourced research projects and collaborations will benefit from data-sharing by being able to publish more and to become dominant voices in debates about antimalarials. Mindful of the importance of advancing science collectively and with the buy-in and participation of researchers based in the global South, WWARN has worked with collaborators in over 280 institutions globally to develop and update its scientific, technical, ethical and governance frameworks to promote equity in data sharing. Key aspects of these efforts which address the primary concerns of the research community are capacity strengthening and technical support in data standardisation and quality, as well as inclusion of primary data generators in any secondary analyses that include their data.

The impact of these efforts is demonstrated by the size of the WWARN platform which, thanks to the contributions of the global malaria research community, now holds over 80% of the world’s individual patient clinical trial data on artemisinin-based combination antimalarials. Evidence generated from these data have been used to inform WHO Treatment Guidelines, and to optimise treatment regimens, especially for vulnerable groups including pregnant women, infants and malnourished children, and provides evidence to inform the development of new antimalarial drugs.