WorldWide Antimalarial Resistance Network (WWARN)  
Efforts to “level the playing fields” for data sharing and re-use by researchers in malaria endemic countries

Professor Karen I Barnes  
Division of Clinical Pharmacology | University of Cape Town (UCT)  
Director: Pharmacology | WorldWide Antimalarial Resistance Network (WWARN)  
Founding Director | MRC Collaborating Centre for Optimising Antimalarial Therapy (CCOAT)
Mission

To accelerate the effective treatment and control of infectious diseases by **strengthening research** and the generation of **evidence for policy** through **equitable data use**.

- Has over 2,000 global research contributors
- Hosts data from more than 1 million patient infections
- Works on 16 research themes with more in the pipeline
- International team in Asia, Africa, Europe, Latin America
WWARN, the mother of the Infectious Diseases Data Observatory (IDDO)

MALARIA (WWARN)  COVID-19  VISCERAL LEISHMANIASIS  MEDICINE QUALITY  SCHISTOSOMIASIS  SOIL-TRANSMITTED HELMINTHIASES
EBOLA  CHAGAS

IDDO  INFECTIOUS DISEASES DATA OBSERVATORY

ANTIMICROBIAL RESISTANCE  SCRUB TYPHUS

MELIOIDOSIS  LYMPHATIC FILARIASIS  NOMA  MYCETOMA  TRACHOMA  HIV

Research themes:  active  building  scoping

IDDO: Achieving economies of scale
A Pioneer Advancing Equitable and Useful Data sharing

Perspective

Avoiding Data Dumpsters — Toward Equitable and Useful Data Sharing

Laura Merson, Oumar Gaye, M.D., Ph.D., and Philippe J. Guerin, M.D., Ph.D.

ANALYSIS

Beyond open data: realising the health benefits of sharing data

Accessible data are not enough. We need to invest in systems that make the information useful, say Elizabeth Pisani and colleagues

Ownership? Compliance? Governance?
Obstacles to data sharing and re-use

MISSING DATA
As research articles age, the odds of their raw data being extant drop dramatically.

Data extant (assuming author responded)

0 0.25 0.50 0.75 1.00

Age of paper (years)

5 10 15 20
Overcoming obstacles 1: Tools and Resources

Tools & resources

The Tools and Resources page is a platform that has tools and services to help you develop and gather research evidence in a standardised way. Navigate through the different components below to access the various resources that can support you to generate quality data from malaria studies.

Search our tools and resources...  SEARCH  or  VIEW ALL RESOURCES

Malaria Clinical Trials Toolkit

Analytical Tools
Analytical tools that can be used in different disciplinary settings.

Procedures
Overcoming obstacles 2: Data curation enables re-use

- Diverse contributed data
- Standardisation of data to CDISC
- Integration of diverse data in repository
- Data inventory, ready to share and re-use

FREQUENCY OF WWARN DATASET RE-USE

How often a dataset was re-used

Integration of diverse data in repository

"Re-use ready data"
Overcoming obstacles 3: Study groups

Enhancing the value of existing data globally for generating new evidence to inform public health action

E.g. IPD meta-analyses:

- Greater power & increased validity and generalisability
- Sufficient sample size to examine vulnerable populations

- Pooled scientific expertise
- Equitable benefit from pooled analyses
Overcoming obstacles 4: Building capacity

- Study groups

- Successful training workshops on data management, data sharing and individual patient data (IPD) meta-analysis in East, West and Southern Africa

- Hosting Postgrad students and EDCTP / TDR clinical research and development fellows from LMICs to gain the skills required to lead future efforts to make the best use of available data to inform policy and practice.
Achieving Impact: Generating Evidence for Policy

- Synthesize evidence
- Re-use ready data
- Expedite data sharing
- Produce evidence & tools to enhance primary data collection
- Evaluate practice
- Implement evidence
- Disseminate evidence to policy makers e.g. WHO, national MoH,
- Disseminate evidence to clinicians, pharma, researchers, patients
Conclusion
Equitable, impactful data sharing requires more than just publisher / funder mandates and a FAIR data repository.

Recommendations
• **Continue to invest** in readily accessible resources (both disease-specific and generic) needed to **enhance the quality and efficiency** of primary data collection, **data sharing and secondary analyses**.
• **Ensure sustainability** of equitable, impactful FAIR data platforms supporting poverty-related disease research communities (both disease-specific and generic) with longer-term funding.
• **Better recognition** of data sharing and secondary analyses in academic promotion criteria, including in LMIC Research institutions.