

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

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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**.

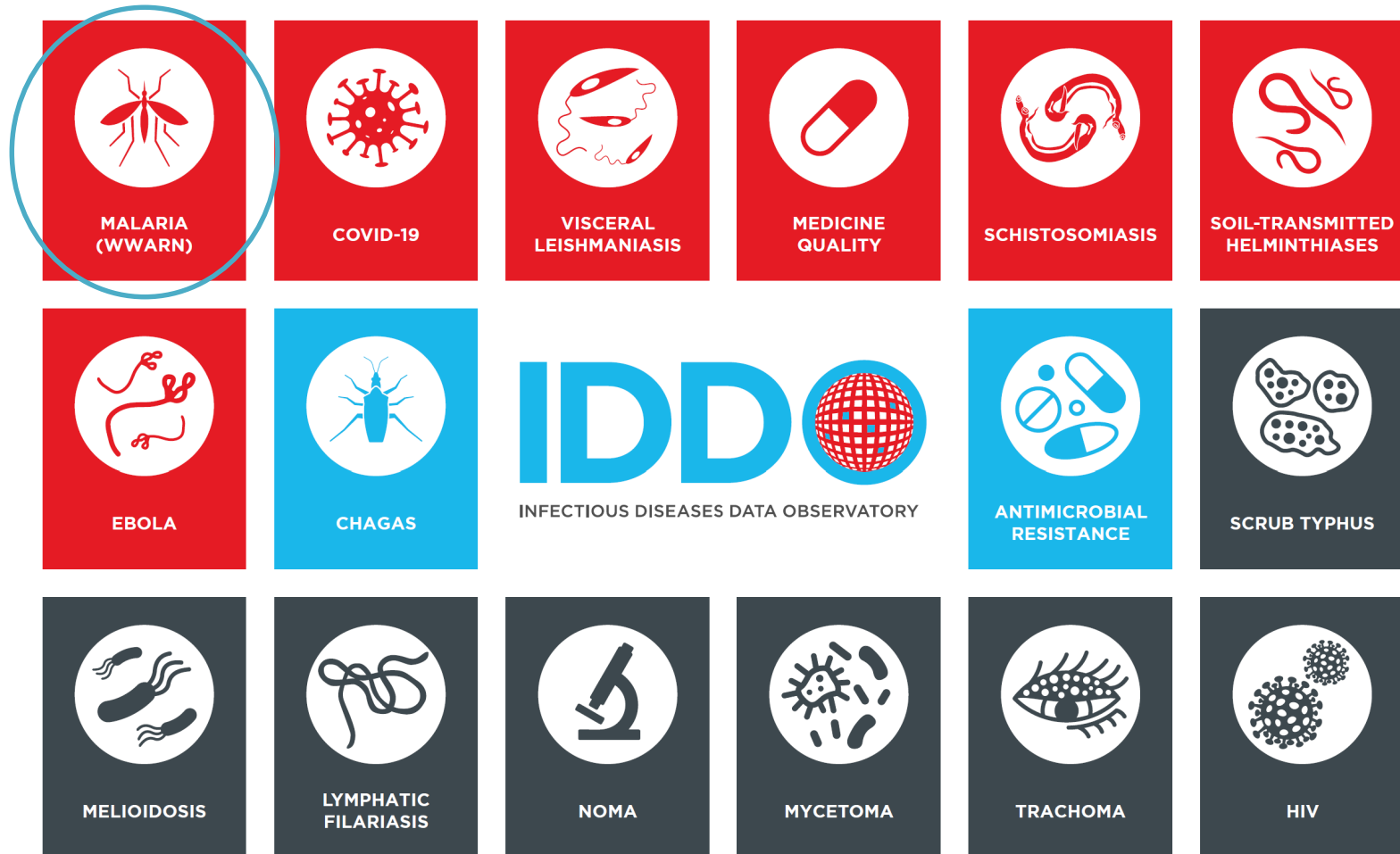
Has over 2,000
global research
contributors

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)



Research themes: ■ active ■ building ■ scoping

Learn more: iddo.org info@iddo.org [@IDDOnews](https://twitter.com/IDDOnews)

IDDO: Achieving economies of scale

A Pioneer Advancing Equitable and Useful Data sharing



The NEW ENGLAND
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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.

N Engl J Med 2016; 374:2414-2415 | June 23, 2016 | DOI: 10.1056/NEJMp1605148

thebmj

BMJ 2016;355:i5295 doi: 10.1136/bmj.i5295 (Published 10 October 2016)

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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



For research on
diseases of poverty

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Ownership?
Compliance?
Governance?

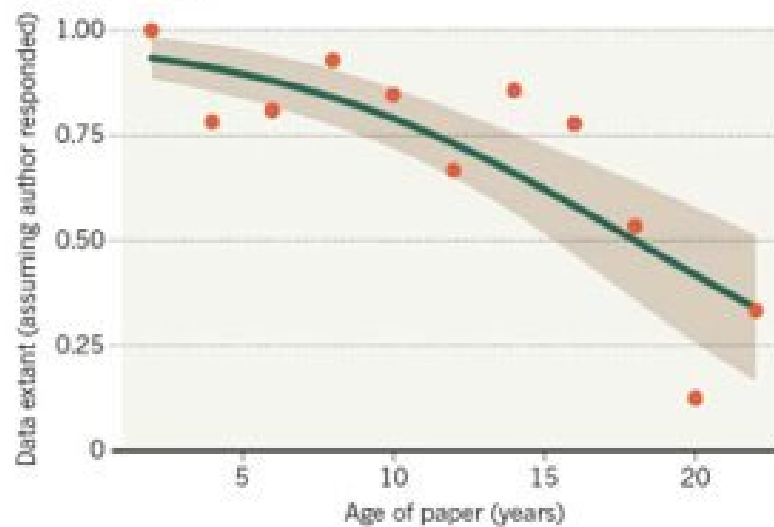


Obstacles to data sharing and re-use



MISSING DATA


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



Overcoming obstacles 1: Tools and Resources

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Tools & resources

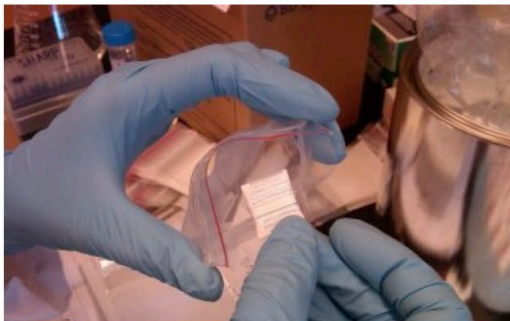
The Tools and Resources page is a platform that has tools and services to help you develop and gather research evidence in a standardised way. Navigate through the different components below to access the various resources that can support you to generate quality data from malaria studies.

Search our tools and resources...

 [SEARCH](#)

or

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Malaria Clinical Trials Toolkit



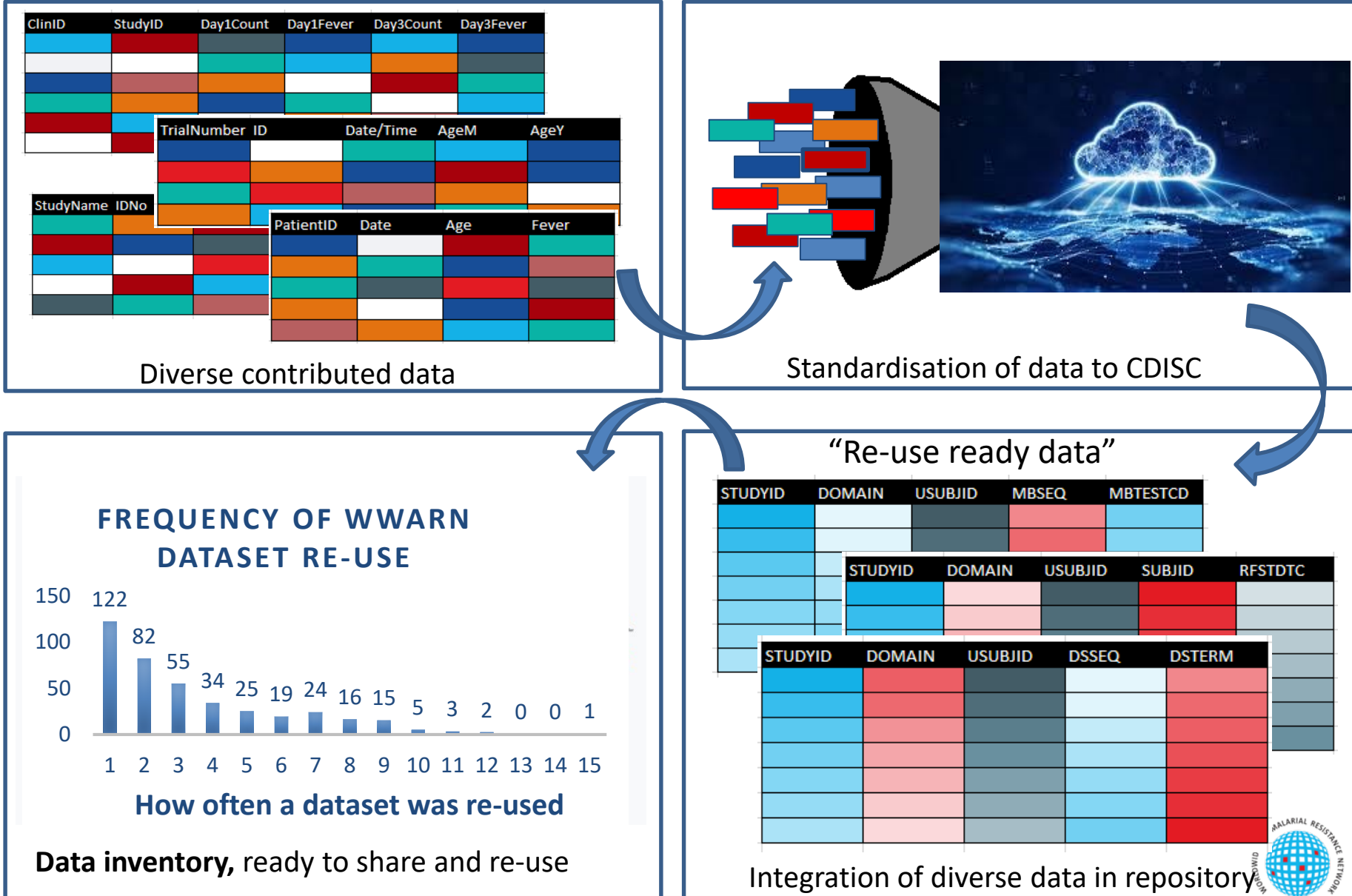
Analytical Tools

Analytical tools that can be used in different disciplinary settings.



Procedures

Overcoming obstacles 2: Data curation enables re-use



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



WWARN

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Credit: Dominic Chavez, World Bank

Study groups

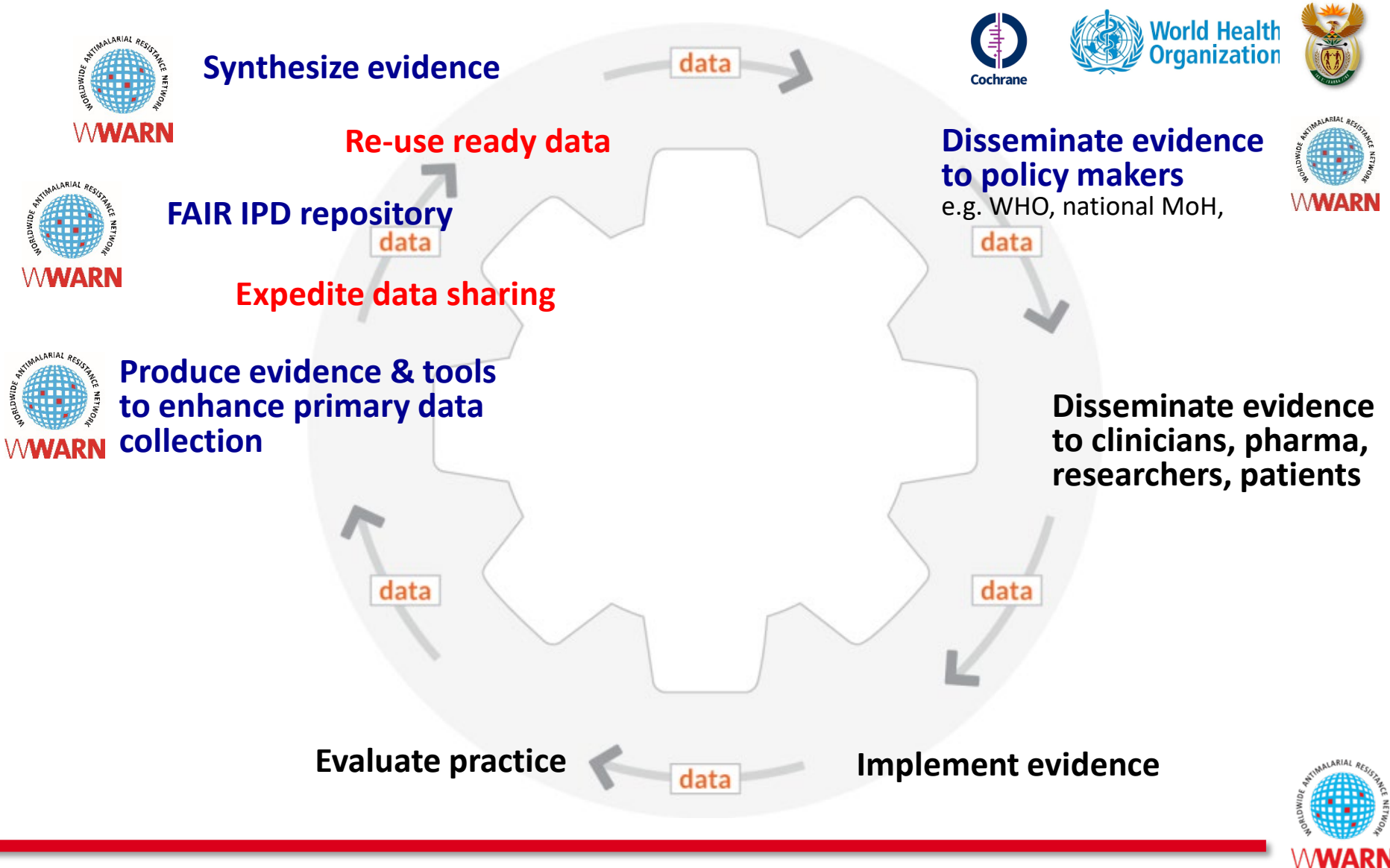
WWARN facilitates a number of collaborative groups to undertake pooled analyses of data to answer specific research questions about **malaria drug resistance**. Pooling data sets from multiple studies increases sample sizes, so that trends or sub-population effects can be identified with greater certainty. By working together and combining data from different regions, the groups aim to improve the understanding of resistance and strengthen global efforts to control and eventually eliminate malaria.

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



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.

Thank you



SUPPORTING THE MALARIA RESEARCH COMMUNITY

THROUGH HIGH-QUALITY ANALYSIS, TOOLS AND A PLATFORM FOR COLLABORATION

EXTERNAL QUALITY
ASSURANCE provided to **69**  laboratories in **28** countries



A NETWORK of **280**
collaborating organisations worldwide



Multidisciplinary
SCIENTIFIC
groups



>600
MALARIA STUDIES

=

>150,000
individual
patient data sets
available to
study groups

≈

80% OF THE WORLD'S
ARTEMISININ BASED
COMBINATION
THERAPY (ACT) DATA



A TOOLKIT
of resources

www.wwarn.org

