

Building a visceral leishmaniasis data-sharing platform to optimise treatment and inform future research

Philippe Guerin on behalf of the VL Data Platform

ASTMH 2017

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Twitter: @IDDOnews

Data sharing requirements

Funders



Journals



Annals of Internal Medicine

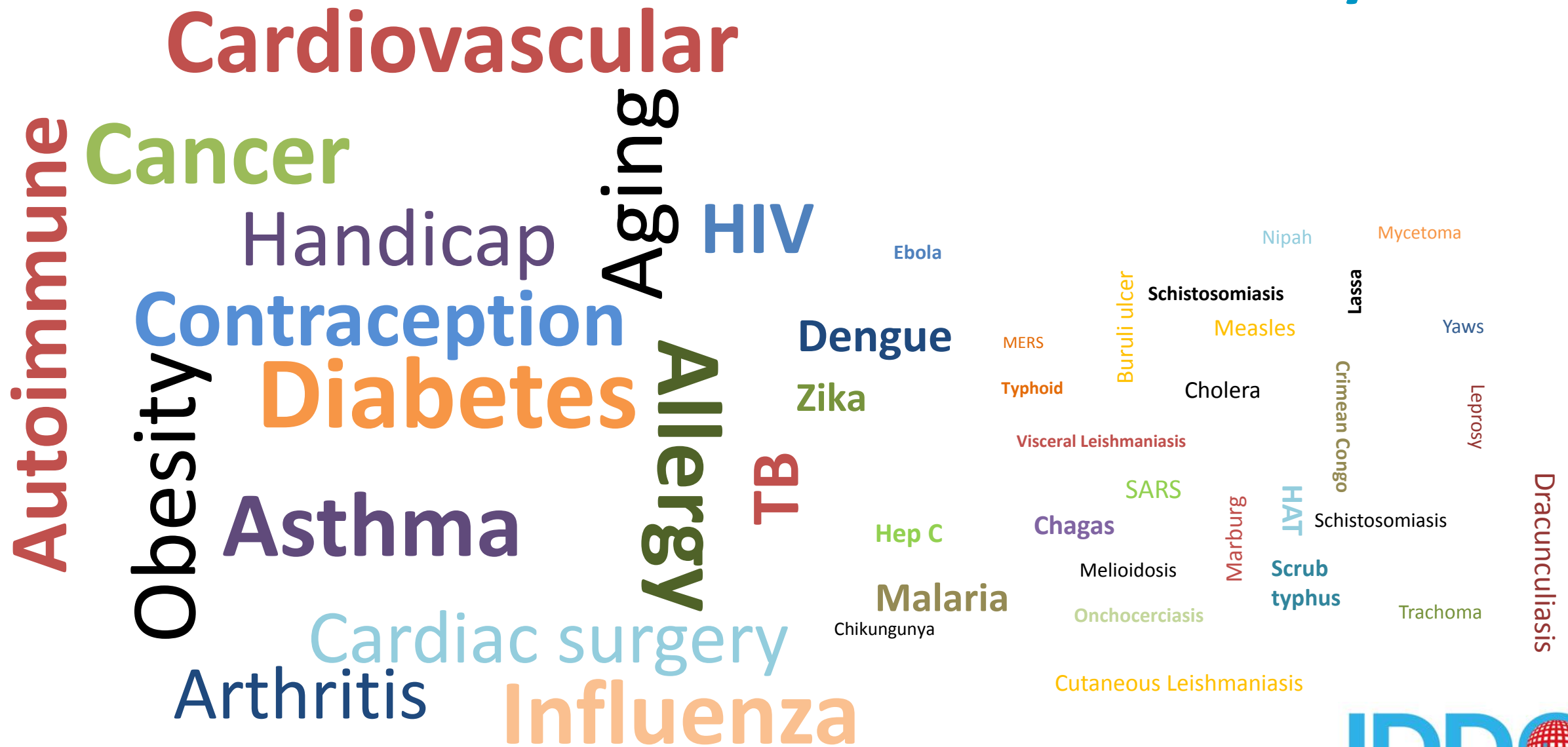
EDITORIAL

Data Sharing Statements for Clinical Trials: A Requirement of the International Committee of Medical Journal Editors

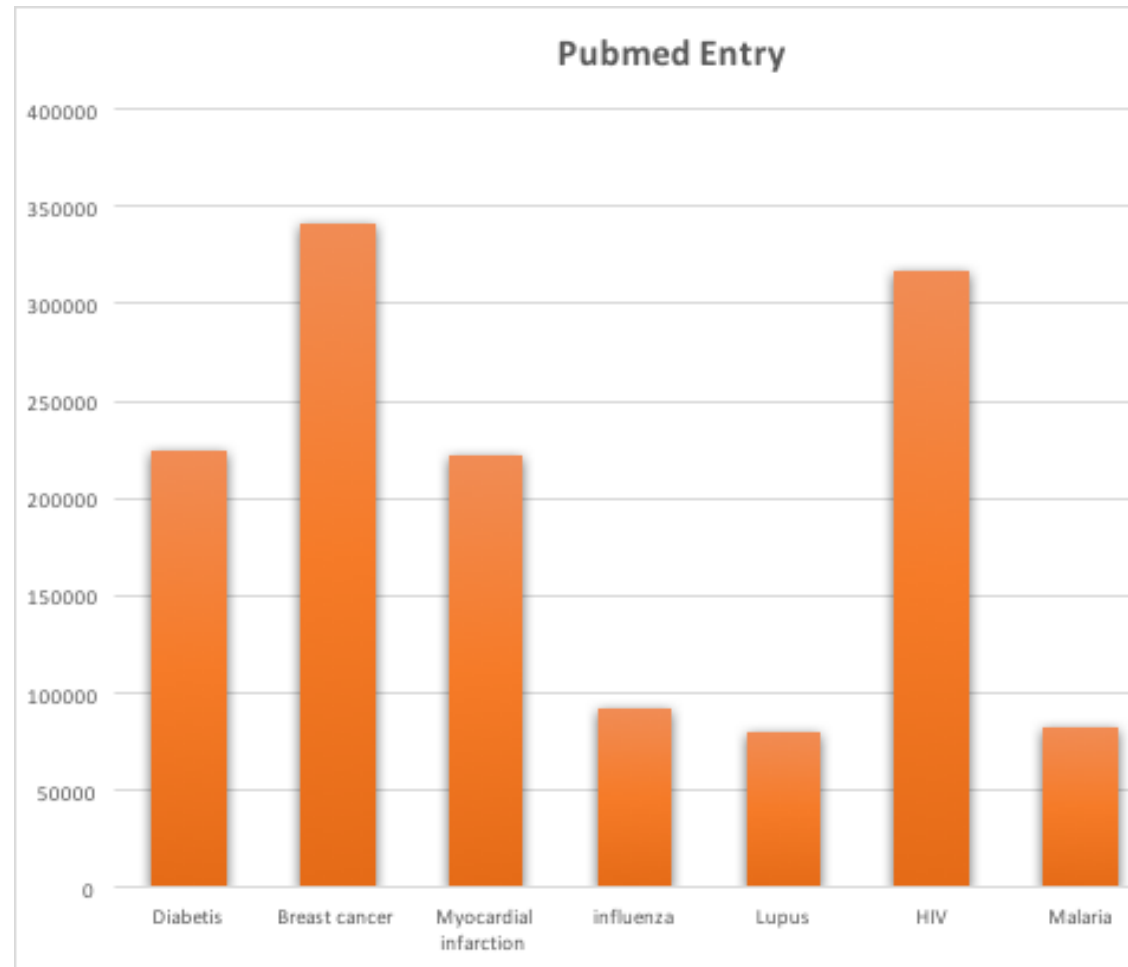
Public Health agencies



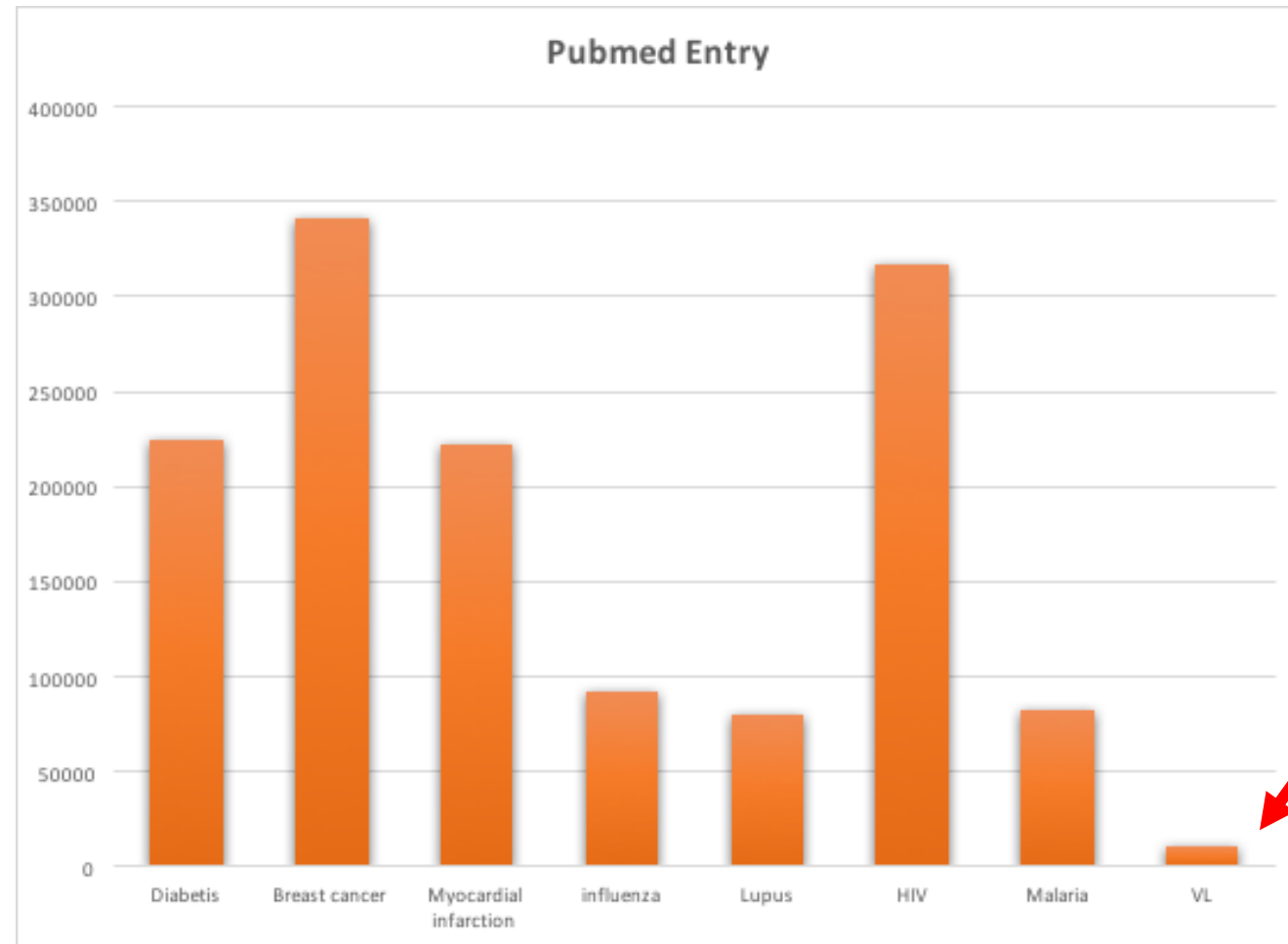
Data reality check



Proxy of “Interest”

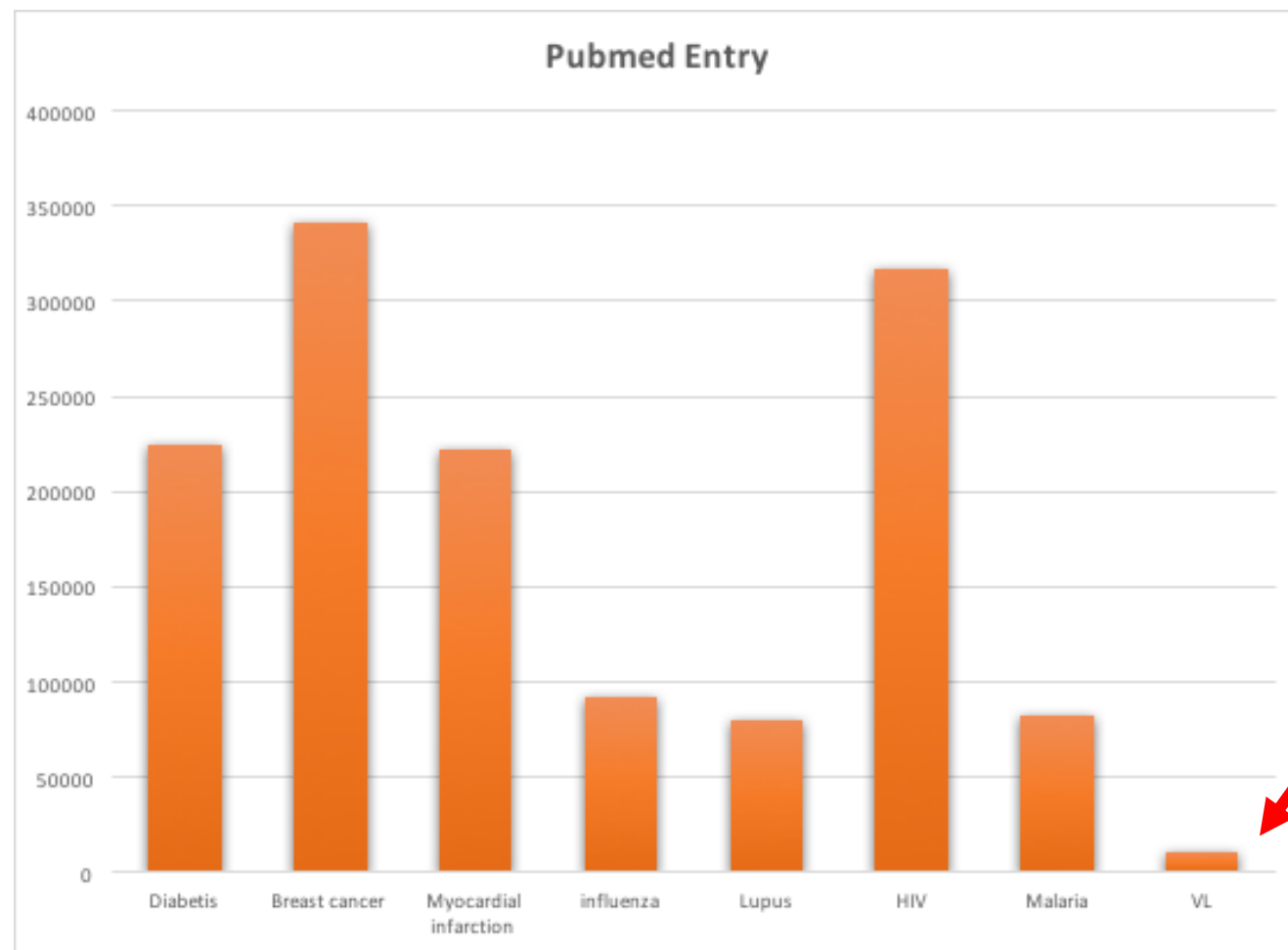


Proxy of “Interest”



10960 for VL

Proxy of “Interest” & Resources



10960 for VL

Data Imbalance

- **Poverty-related & emerging infections vs other diseases**
 - Lower data volume, variable in quality
 - Scattered geographically
 - **Challenges** in patient recruitment
 - Limited commercial interest
- **Challenges of funder and journal data-sharing policies**
 - Disadvantages for developing country investigators
 - Ethical challenges: Benefits vs risks
 - Data security and privacy protection
 - Cost

Understanding factors affecting efficacy

Drugs	SSG	Ampho B Liposomal	Ampho B deoxycholate	MIL	PM sulphate	SSG+PM	LAB+SSG	LAB+MIL	PM+MIL
Clinical efficacy									
Asia	35-95% (depending on areas)	> 97% all regions	> 97%; single dose: > 96%	94-97% (India)	94% (India)	93,8% (India)	> 97%	> 97%	> 97%
Africa	93%	33 - >97% (depending on areas)	Not fully established	72%	84%	91%	87%	79%	Not documented
Resistance	As high as 60% (India)	Not documented	Not documented	20% (Nepal)	Lab isolates (easily)	Lab isolates (easily)	Lab isolates	Lab isolates	Lab isolates (easily)

Extreme variations in treatment response observed by drugs and regions

Source DNDi

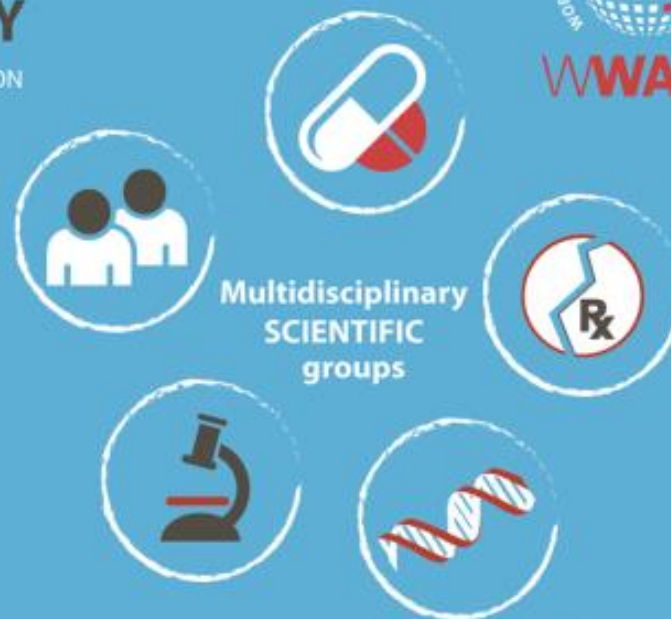
SUPPORTING THE MALARIA RESEARCH COMMUNITY

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

EXTERNAL QUALITY
ASSURANCE provided to **60**  laboratories in **27** countries



A NETWORK of **262**
collaborating organisations worldwide



Multidisciplinary
SCIENTIFIC
groups



WWARN



400
CLINICAL TRIALS

=



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



Could available data be used to optimise treatment outcome?

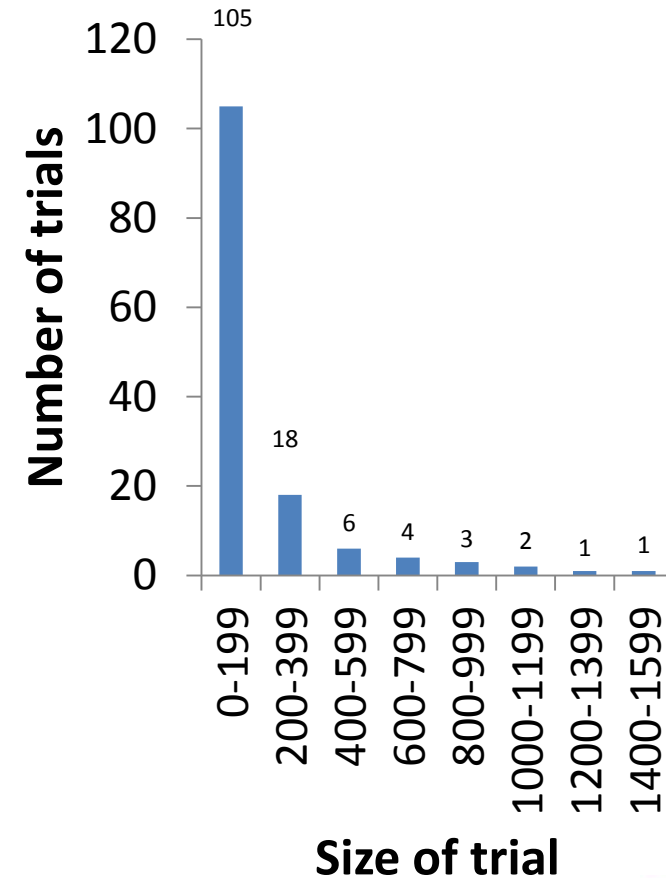
RESEARCH ARTICLE

Systematic review of clinical trials assessing the therapeutic efficacy of visceral leishmaniasis treatments: A first step to assess the feasibility of establishing an individual patient data sharing platform

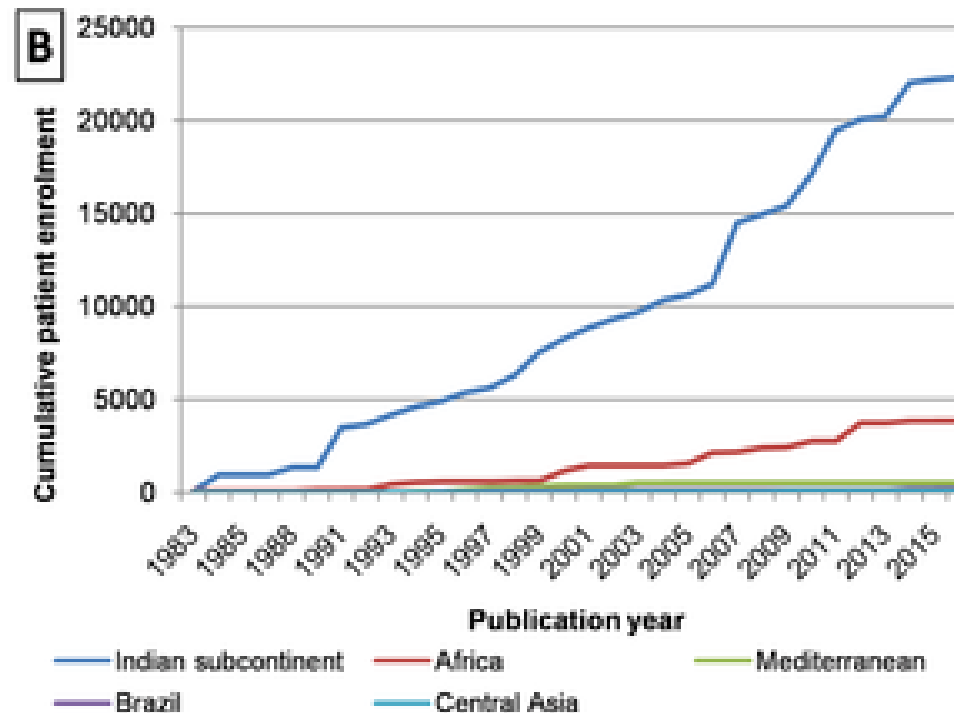
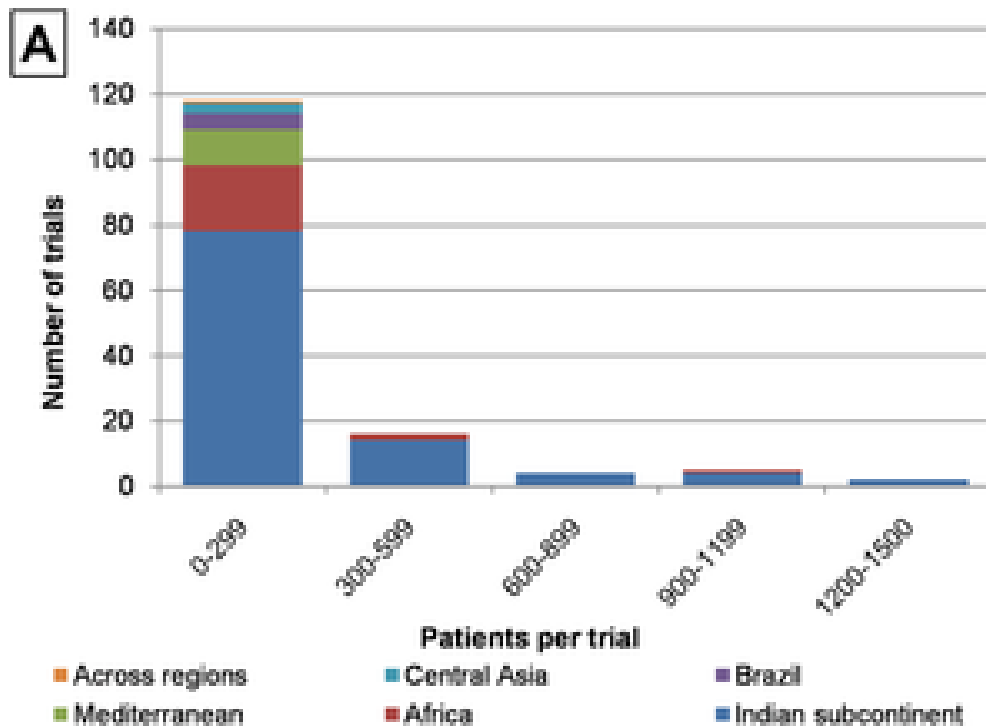
Jacob T. Bush^{1,2}, Monique Wasunna³, Fabiana Alves⁴, Jorge Alvar⁴, Piero L. Olliaro^{1,5}, Michael Otieno^{1,2,3}, Carol Hopkins Sibley^{1,2,6}, Nathalie Strub Wourgaft^{4*}, Philippe J. Guerin^{1,2*}

Clinical trials landscape

- 141 clinical studies on VL drugs
 - 25,865 patients
 - Most trials **enroll less than 200**
- 1,379 patients in completed, unpublished trials
- 9,802 in active trials
 - **Total > 37 000 patients**

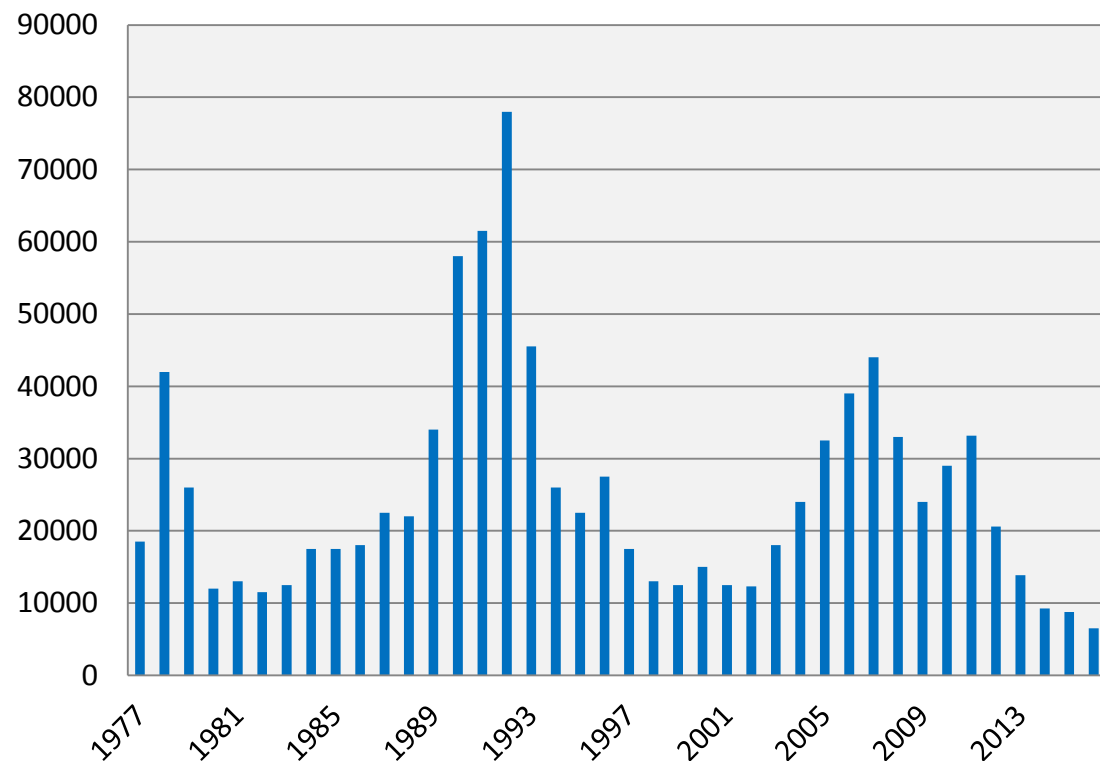


A perishable but transferable knowledge



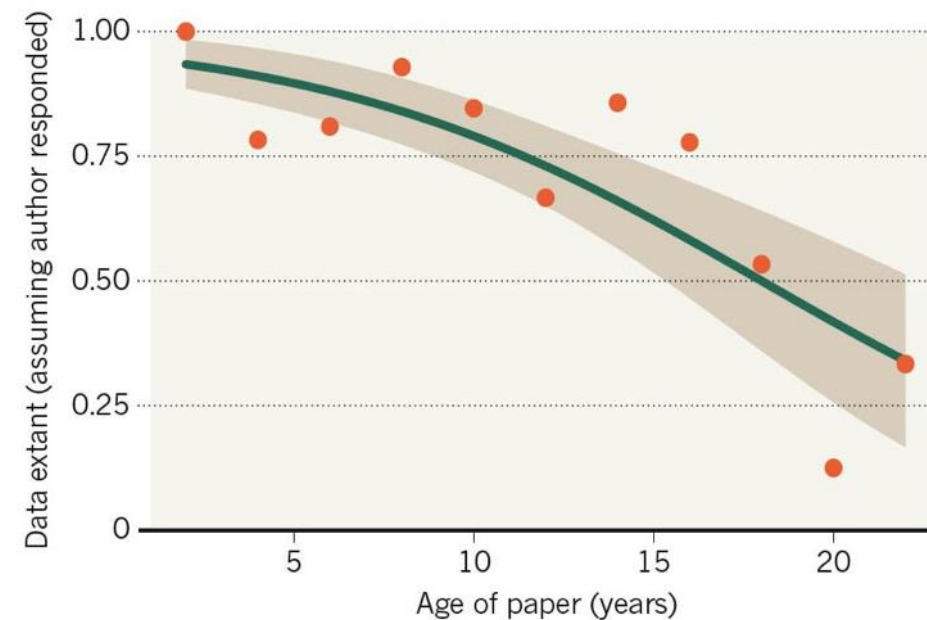
Guarding the value of data: lesson learned in Asia

India VL trend (1977-2016)



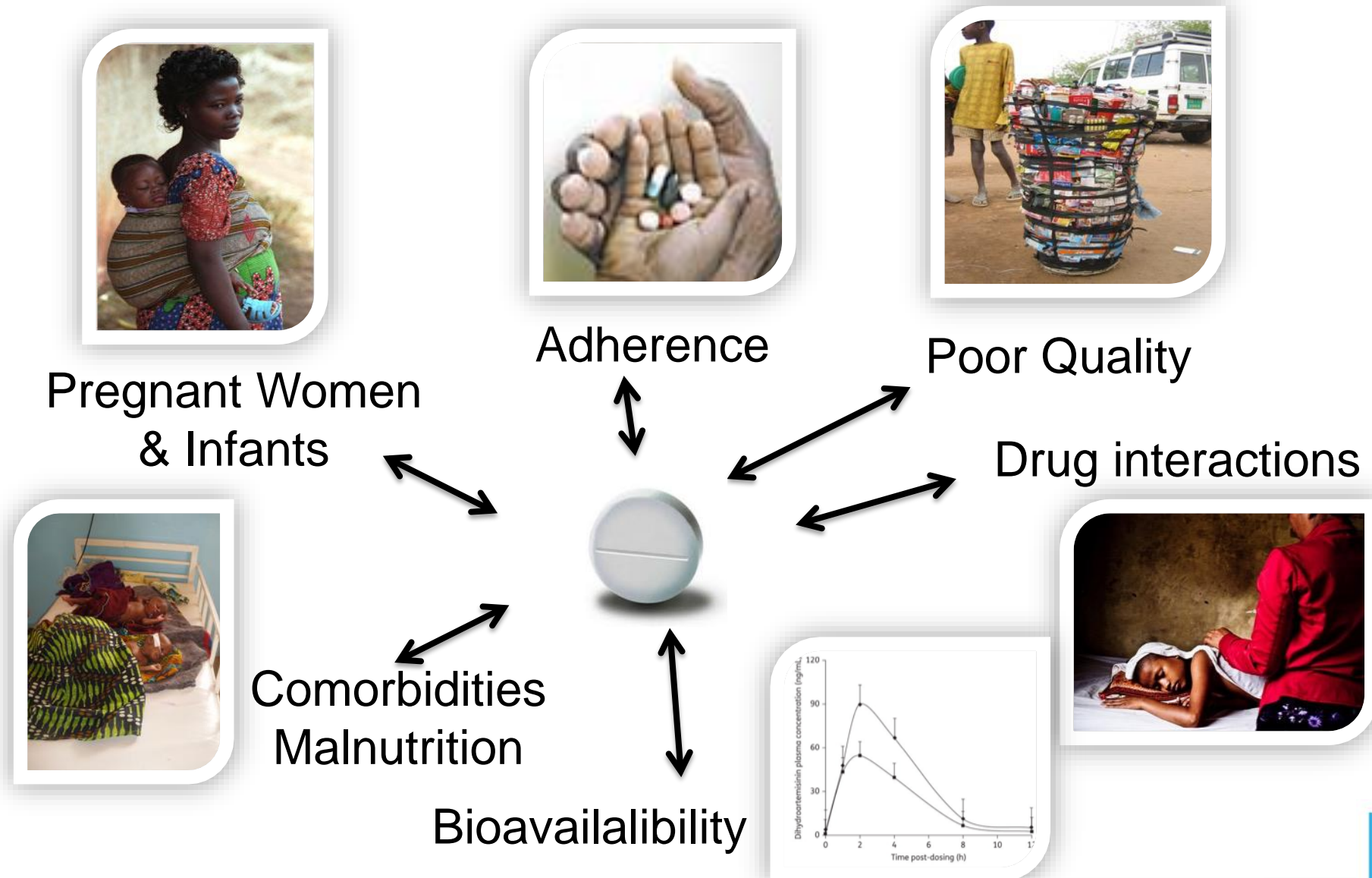
MISSING DATA

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



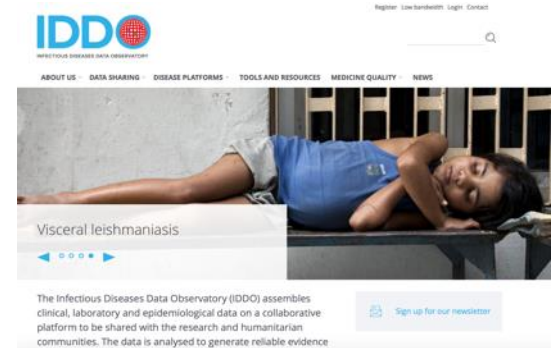
Vines *et al.* Current Biology 2014

Identifying factors affecting drug efficacy



Benefits of data platforms

- Larger patient numbers allow for greater power
- Sufficient size to examine **sub-populations**
 - Infants, pregnant women, malnourished children
- Better historical baseline for evaluating treatments
- Increased validity of findings
- **Provide the forum for standards development for prospective studies**
- Inform new drug development



VL data platform - Scientific Advisory Committee

- Defining the governance
- Developing research agenda with the scientific research community



Prof. Simon Croft
LSHTM



Prof. Shyam Sundar
Banaras Hindu



Prof. Marleen Boelaert
Institute of Tropical Medicine



Dr. Jorge Alvar
DNDi



Dr. Koert Ritmeijer
MSF



Prof. Ahmed Mudawi Musa
Institute of Endemic Diseases



Dr. Dinesh Mondal
icddr,b



Observer
Prof. Hannah Akuffo
Karolinska Institutet

Developing a Data Platform which makes sense for the VL scientific community requires dialogue and innovation



Image: Anita Khemka/DNDi

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In partnership with



Thank you

