



Organising national research data management services

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Research article

Open Access

Rectal artemisinins for malaria: a review of efficacy and safety from individual patient data in clinical studies

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Harin Karunajeewa⁴ and Max Petzold^{2,5}

HEALTHY LIVING

The Latest On Zika: Brazil Isn't Sharing Data

Scientists say they're having trouble analyzing the outbreak because they don't have enough up-to-date information.

02/04/2016 03:43 pm ET | Updated Feb 05, 2016



Erin Schumaker 

Senior Healthy Living Editor, The Huffington Post



MARIO TAMA VIA GETTY IMAGES

Health workers pass out information on mosquito protection to people arriving in the baggage claim area at Guararapes Gilberto Freyre International Airport on February 4, 2016 in Recife, Pernambuco state, Brazil. Officials say

BILL & MELINDA GATES FOUNDATION OPEN ACCESS POLICY

UNDERLYING DATA GUIDELINES

+ SHARE | SECT

The [Open Access Policy](#) requires that data underlying published research results will be accessible and open immediately.

The following guidelines focus on data underlying published research. Activities around pre-publication data planning, collection, analysis, storage, sovereignty, informed consent, interoperability, and the use of disciplinary standards are addressed at the individual grant and contract level by the grantee and program officer during the proposal stage.

These guidelines are aligned with existing industry best practices, including data availability policies required by several publishers. As new practices emerge, the guidelines will be reviewed and updated as needed.

What is underlying data?

Underlying data encompasses all primary data, associated metadata, and any additional relevant data necessary to understand, assess, and replicate the reported study findings in totality.

Underlying data can be compiled into any file type, including any necessary access instructions, code, or supporting information files, to ensure the file(s) can be accessed and used by others.

Note: We do not require sharing of data that is ethically unsound or legally encumbered.

Why is access to underlying data important?

Providing access to underlying data is key in fulfilling the foundation's mission of rapid and free exchange of scientific ideas to move humanity forward by improving and saving lives. Without barriers the scientific community can freely benefit from data and build upon each other's work.

NATURE | NEWS



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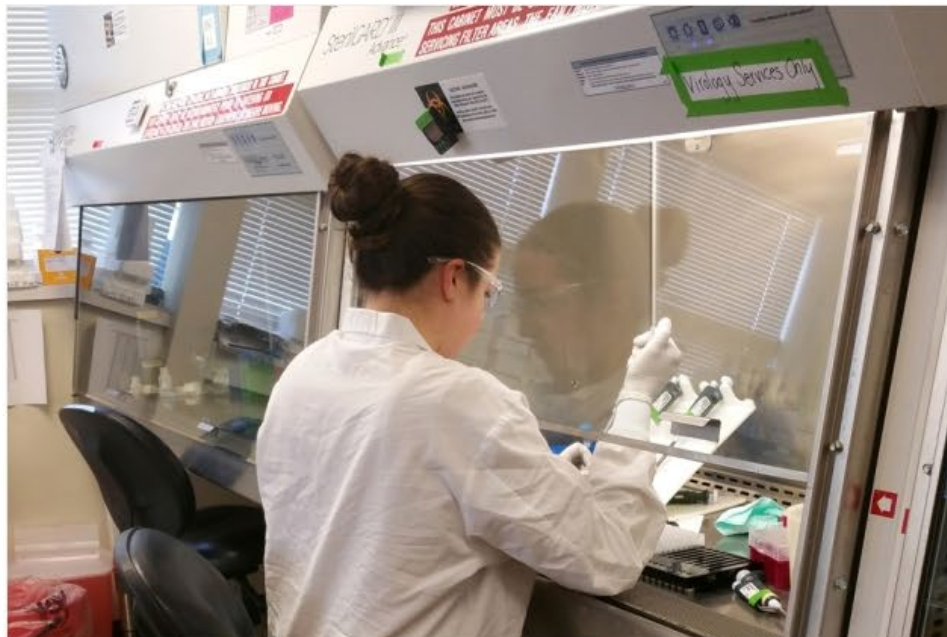
Zika researchers release real-time data on viral infection study in monkeys

Raw data from macaque experiment published daily online.

[Declan Butler](#)

23 February 2016

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Kristi L. Hall

Gabrielle Lehrer-Brey, part of a team that is experimentally infecting macaques with Zika virus, works with



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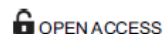
RESEARCH ARTICLE

The Willingness to Pay for Vaccination against Tick-Borne Encephalitis and Implications for Public Health Policy: Evidence from Sweden

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Data Availability Statement: The dataset is available via Swedish National Data Service: <http://snd.gu.se/sv/catalogue/study/SND0987>, the dataset has doi:[10.5878/002744](https://doi.org/10.5878/002744).

Published: December 7, 2015

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Abstract

The increasing incidence of tick-borne encephalitis (TBE) in Sweden and several other European countries has sparked a discussion about the need for a public vaccination strategy. However, TBE vaccination coverage is incomplete and there is little knowledge about the factors influencing vaccination behavior. Based on a survey of 1,500 randomly selected respondents in Sweden, we estimate vaccination coverage in areas with different TBE risk levels and analyze the role of vaccine price and other factors influencing the demand for vaccination. First, we find that the average rate of TBE vaccination in Sweden is 33% in TBE risk areas and 18% elsewhere. Income, age and risk-related factors such as incidence of TBE in the area of residence, frequency of visits to areas with TBE risk, and experience with tick bites are positively associated with demand for TBE vaccine. Next, using contingent valuation methodology, we estimate the willingness to pay for TBE vaccination among the unvaccinated respondents and the effect of a possible subsidy. Among the unvaccinated respondents in TBE risk areas, we estimate the mean willingness to pay for the recommended three doses of TBE vaccine to be 465 SEK (approximately 46 euros or 40% of the current market price). We project that a subsidy making TBE vaccines free of charge could increase the vaccination rate in TBE risk areas to around 78%, with a larger effect on low-income households, whose current vaccination rate is only 15% in risk areas. However, price is not the only factor affecting demand. We find significant effects on vaccination behavior associated with trust in vaccine recommendations, perceptions about tick bite-related health risks and knowledge about ticks and tick-borne diseases. Hence, increasing knowledge and trust, as well as ease of access to vaccinations, can also be important measures for public health agencies that want to increase the vaccination rate.



FAIR – Findable, Accesible, Interoperable, Reusable

- As open as possible, as closed as necessary!
 - 15 guiding principles by FORCE11 to simplify life of the scientists
 - FAIR is
 - Not a standard
 - Not equal to “Open” or “Free”
 - Both for humans and machines
 - Data
 - Are often Open but not FAIR
 - Could be closed but perfectly FAIR
 - That is not FAIR are pretty re-useless
- 

EOSC is moving – Sweden needs to add on infrastructures

Data management planning becomes a standard scientific practice **early** in the research process

European Open Science Cloud (EOSC) as a **trusted**, open environment

EOSC as a **federation** of research data infrastructures

COMMISSION RECOMMENDATION of 25.4.2018

On access to and preservation of scientific information

Making the necessary **funding** for data management available

Unique **identification**

Creation of **incentive** schemes, reward systems and education and training programmes for researchers

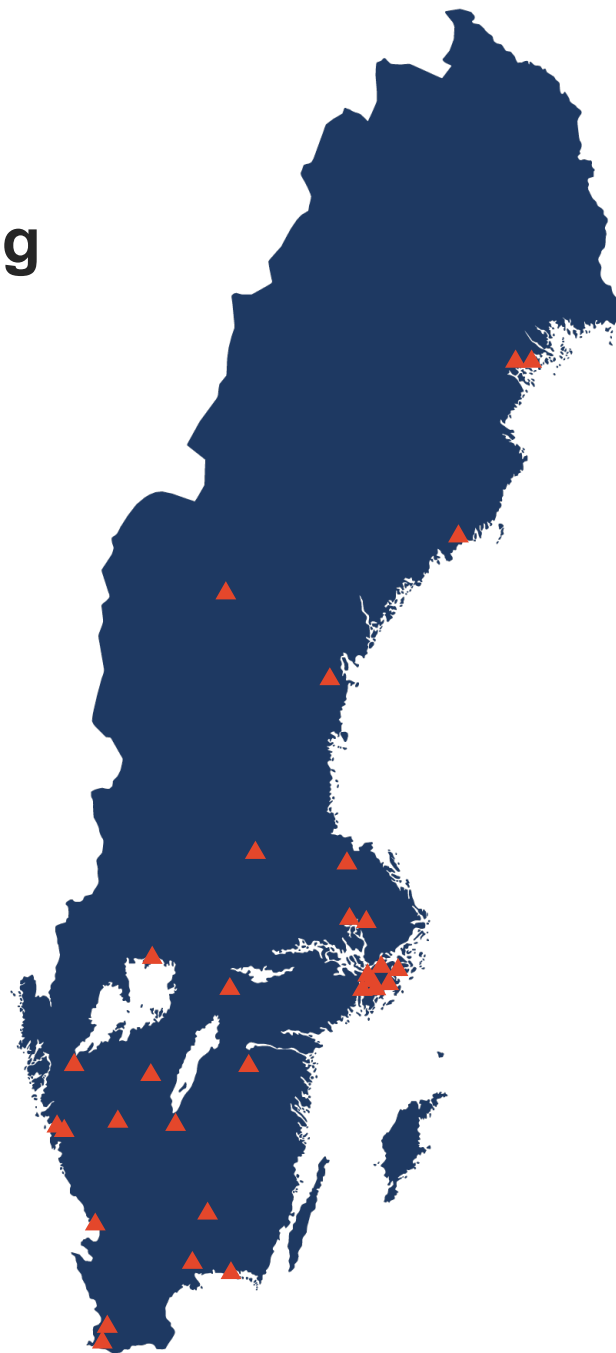
Concrete objectives and indicators of measure progress

SND 2.0 Where we are now

SND members

- bottom up with national funding

Mittuniversitetet
Högskolan Dalarna
Örebro universitet
Karlstads universitet
Högskolan i Skövde
Högskolan Väst
Högskolan i Borås
Göteborgs universitet
Chalmers tekniska högskola
Jönköping University
Högskolan i Halmstad
Lunds universitet
Malmö universitet



Luleå tekniska universitet
Polarforskningssekretariatet
Umeå universitet
Högskolan i Gävle
Uppsala universitet
Sveriges lantbruksuniversitet
Mälardalens högskola
Stockholms universitet
Karolinska institutet
Kungliga tekniska högskolan
Handelshögskolan i Stockholm
Försvarshögskolan
Södertörns högskola
Linköpings universitet
Linnéuniversitetet
Högskolan Kristianstad
Blekinge tekniska högskola

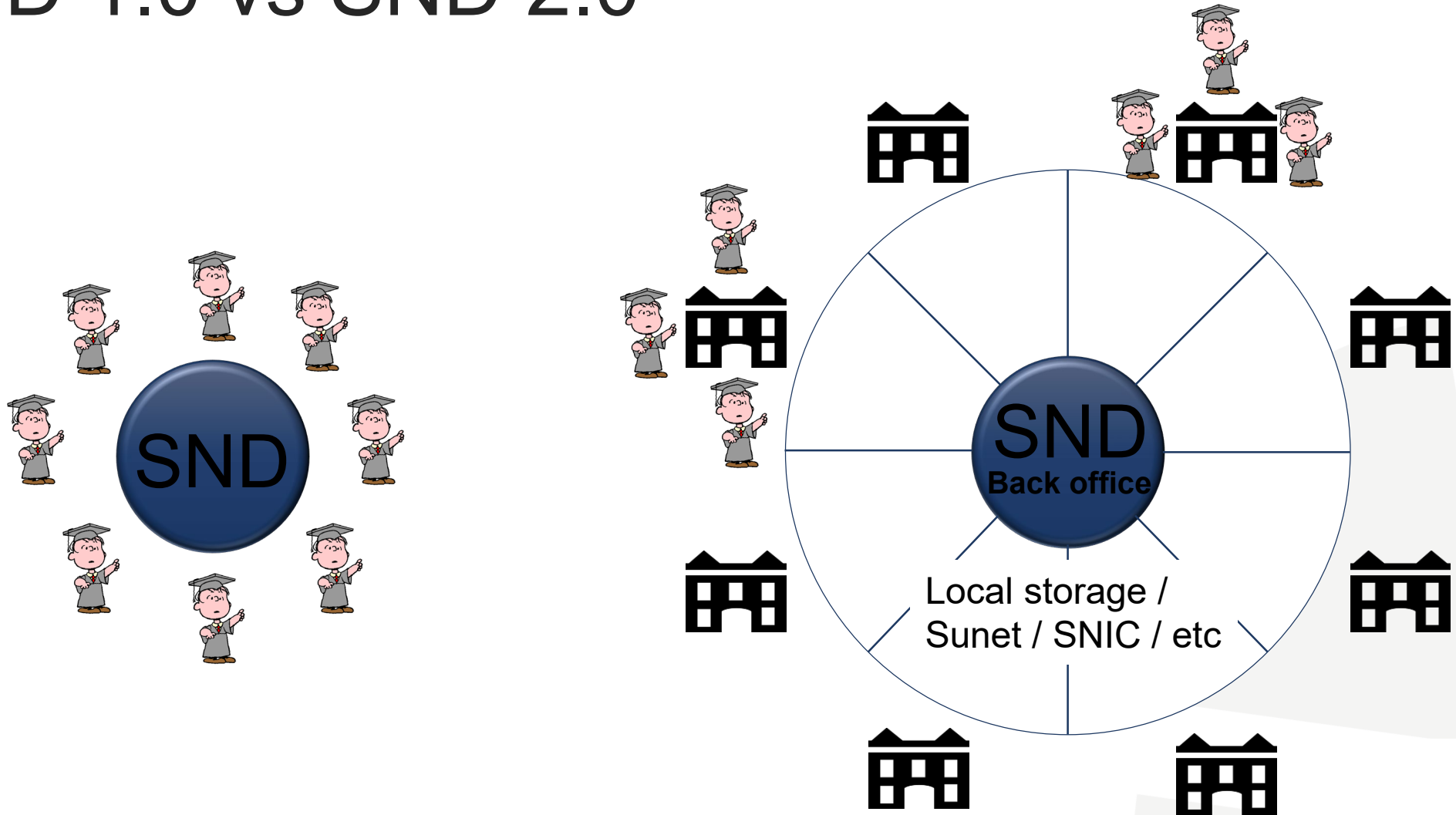


SND – purpose

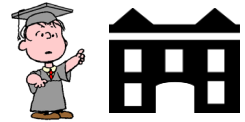
The purpose of SND is to provide a coordinated and secure structure for describing, depositing, sharing, and finding research data:

- All researcher should be able to fulfill the Open Data standards suggested by the universities, funders and journals.
- Researchers should be supported to ensure proper data curation, metadata and legal handling of data (sensitive information, ownership, contracts).
- Built on distributed, secured storage to ensure that the research data is under the control of the university.
- Actively supporting other Open Data initiatives and importing/exporting metadata to other general/specialised portals/repositories.

SND 1.0 vs SND 2.0



SND – Data Flow



Metadata are uploaded to the SND portal.

Data are uploaded to local storage/SUNET/SNIC. Flagged as open or restricted.



Direct access or request to access data



Piloted 2019 with: SNIC (Swestore), SUNET and CTH, KTH, SU, GU, SLU, Borås, Malmö and Polarforskningssekretariatet.

Very important!
LAPTOP LOST
in the bus 345



(Silver macbook pro, lost in the bus, line 345, at South Kensington station on Friday 10th at 7am, within a black bag also containing my ID card)

CRUCIAL scientific data
+ many **YEARS** of
research work inside!

Please bring it back to Imperial College (Prince consort road, between the
bus and Hyde park) or **CALL** me to see how we can proceed.

Thank You!

Max Petzold

max.Petzold@gu.se

www.snd.gu.se



SND

Swedish National Data Service

| Karolinska Institutet - Lund University - Stockholm University - Swedish University of Agricultural Sciences - Umeå University - University of Gothenburg - Uppsala University