

Digital solutions for research in resource poor areas

Experiences from the CYSTINET-Africa project

Jan Knobloch

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The Cystinet Africa Project

Project runtime: October 2016 – October 2021

Countries: Germany, Mozambique, Tanzania and Zambia



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The Research Tasks

The epidemiology of *Taenia solium* cysticercosis/ taeniosis with special emphasis on neurocysticercosis and its related immunological pathomechanisms.

Mozambique

Taenia solium neuro(cysticercosis)/ taeniosis in people living with HIV/AIDS.

Tanzania

Development, evaluation and implementation of a practical health education
Intervention package for prevention and control of *Taenia solium* cysticercosis and taeniosis.

Tanzania

Establishment of an experimental pig model of *Taenia solium* cysticercosis.

Zambia



Experiences and **Lessons learned**

Interdisciplinary Team communication



Hardware / Software Procurement



Infrastructure assessment



Setup and Maintenance



Experiences: Interdisciplinary Team communication



Communication

Interdisciplinary teams

Storage of personal medical information

Different time zones
Different working hours
Different cultures

Different Studies
Different workflows

Different countries
Different data privacy regulations





Lessons learned:

Interdisciplinary Team communication

Issue: Communication can be delayed. Time zones, different working hours, and cultural reasons.

Solution approach: Find agreements on how to reach individual persons quickly – Skype, WhatsApp

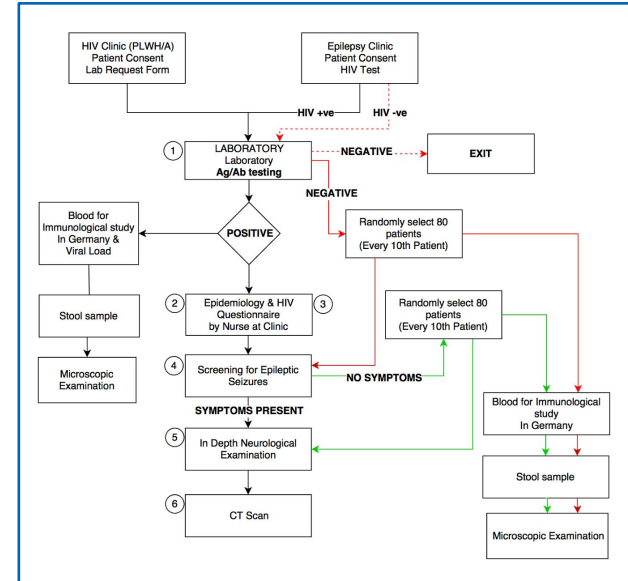
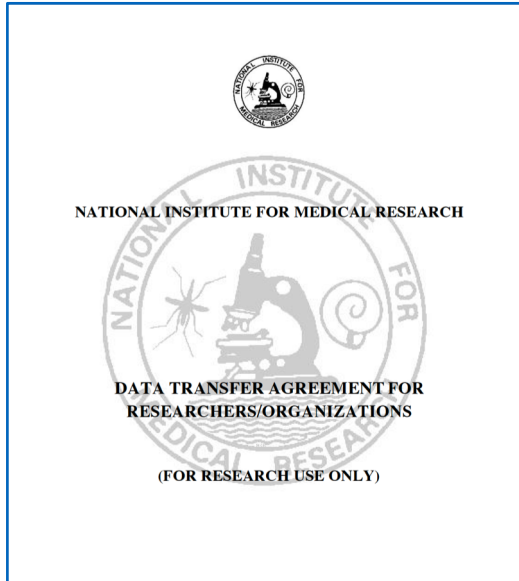
Issue: Often even interdisciplinary teams do not see the full picture of their studies and workflows.

Solution approach: Creation of workflows and SOPs to have a common understanding

Issue: Storage and exchange of medical / personal data over different countries can be cumbersome

Solution approach: Plan way ahead as legal departments and many persons can be involved.

Lessons learned: Interdisciplinary Team communication



Experiences: Infrastructure Assessment



“ Do you have internet?”

“Can you provide a server available via internet?”

„Who is able to support our systems?“



"Is your internet fast?"

“Is your internet reliable?”

“Do you have power backups?”

Lessons learned: Infrastructure Assessment

Issue: How can you verify a reliable location for data storage?

Solution approach: Use existing monitoring software (speedtest.net, statuscake..).
Test power backups (USV). Inspect locations where servers are intended to be placed.

Issue: IT administrators / personal are not necessarily software developers

Solution approach: Make sure to know about individual skills / assets of the IT team
Offer trainings for software development and maintenance if needed.



Experiences:

Hardware / Software Procurement



Proposing specific IT hardware and software components can be difficult.

Newest hardware is often not available in certain regions or will be very expensive. (custom orders)

If new hardware is available there is often no warranty or shops that can execute warranty claims in a certain time / cost perspective

Setup of new equipment can be difficult / time consuming if not done on site

Lessons learned:

Hardware / Software Procurement



Issue: Procuring hardware can be a long term process.

Solution approach: Assure funds are able and allowed to be transferred.

Checkout hardware availability in shops (in multiple locations)

Find (online)shops which allow invoicing as payment method

Issue: Needed hardware is not available in certain regions

Solution approach: Order hardware from abroad and bring it when you travel.

Make sure to test hardware before transfer

Make sure that all needed supplies (e.g. printing paper) are also available.



Experiences: Setup and Maintenance

Using existing software (open source) can reduce costs, finding the right software however can be time consuming and test intensive.

Identifying the right software without defining an actual need for certain workflows can be difficult

Personnel for installing and maintaining servers is crucial but not always available



Lessons learned:

Setup and Maintenance

Issue: Finding qualified personal and resource requirements can be a hard problem

Solution approach: Train and help to setup the needed infrastructure

Provide reliable backups in regions where data loss can occur

If Data exchange agreements allow backup data to different locations

Issue: Using available software always opens up a gap between privacy/security and convenience

Solution approach: Take your time to fully evaluate different options for e.g. Tablet data collection.



Lessons learned:

Setup and Maintenance

In Cystinet we evaluated:

MagPi, EpiCollect and KoboToolbox as frameworks for mobile/offline data collection with the following results (summarized):

MagPi ([**https://home.magpi.com/**](https://home.magpi.com/))

500 dollar per month

EpiCollect ([**https://five.epicollect.net/**](https://five.epicollect.net/))

Free but they may (ab)use your data

KoboToolbox ([**https://www.kobotoolbox.org/**](https://www.kobotoolbox.org/))

Free, but you need technical knowledge to setup and maintain the system



Lessons learned: Setup and Maintenance

EpiCollect:

**Question towards the lead developer
of storing data on our own server**



Mirko Menegazzo Eigentümer +1

Hi, sorry for the confusion. Despite the similar name, Epicollect5 is a brand new tool, sharing just a handful of features with any previous releases. As you found out, no one is willing to give away the kitchen sink, so to speak ;)

[Übersetzen](#)

KoboToolbox:

Open Bugs which could be fixed / addressed

Out of the box KoboToolbox was not working

 `No JSON object could be decoded` when attempting to deploy forms 
#162 by janknobloch was closed on 29 May

Backups have been created but being empty

 Set proper env variable for postgres backups
#160 opened on 28 Jan by Tomatosoup97

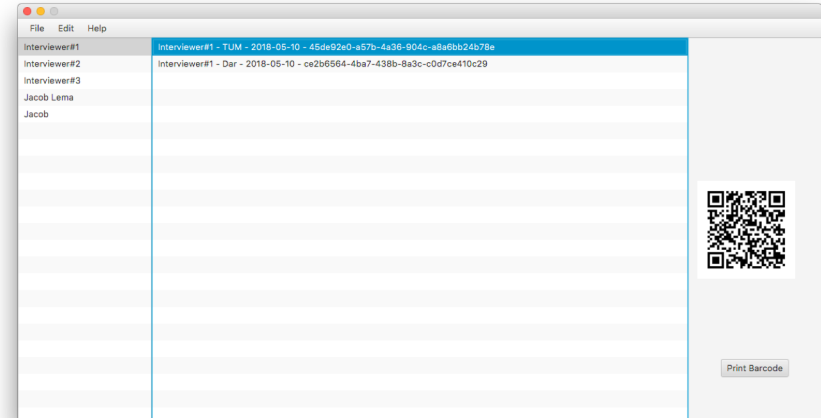
Lessons learned: Setup and Maintenance



Refinement of workflows can introduce gaps of what certain software is capable of providing:

Limitations of data lookup using QR codes

Limitations of printing QR codes for patients / samples



Experiences and **Lessons learned**

Interdisciplinary Team
communication



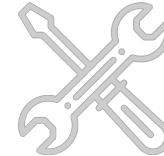
Hardware / Software
Procurement



Infrastructure assessment



Setup and Maintenance





EU-DSVGO Changes

1. Naming and specification of a data privacy officer

2. Strengthening the rights of affected persons (in particular important for medical research)

- **Right to be forgotten**

(you can ask to delete your personal data at any time)

- **Data portability**

(you can ask to retrieve all personal data stored about you at any time)

- **Privacy by Design and Privacy by Default**

(you are only allowed to collect data needed for a dedicated purpose)

