ODK Clinic

Design of a Phone-Based Clinical Decision Support System for Resource-Limited Settings

Yaw Anokwa, Win Ribeka, Martin Were,
Tapan Parikh, Gaetano Borriello

http://opendatakit.org

good morning.

i first want to thank clem mcdonald for giving the opportunity to share my work with all of you. it's a real honor.

my name is yaw anokwa. i'm a ph.d student in computer science from the university of washington and this talk is about the design of a phone-based clinical decision support system for resource-limited settings.

that's a bit of a mouthful so i call the system odk clinic.

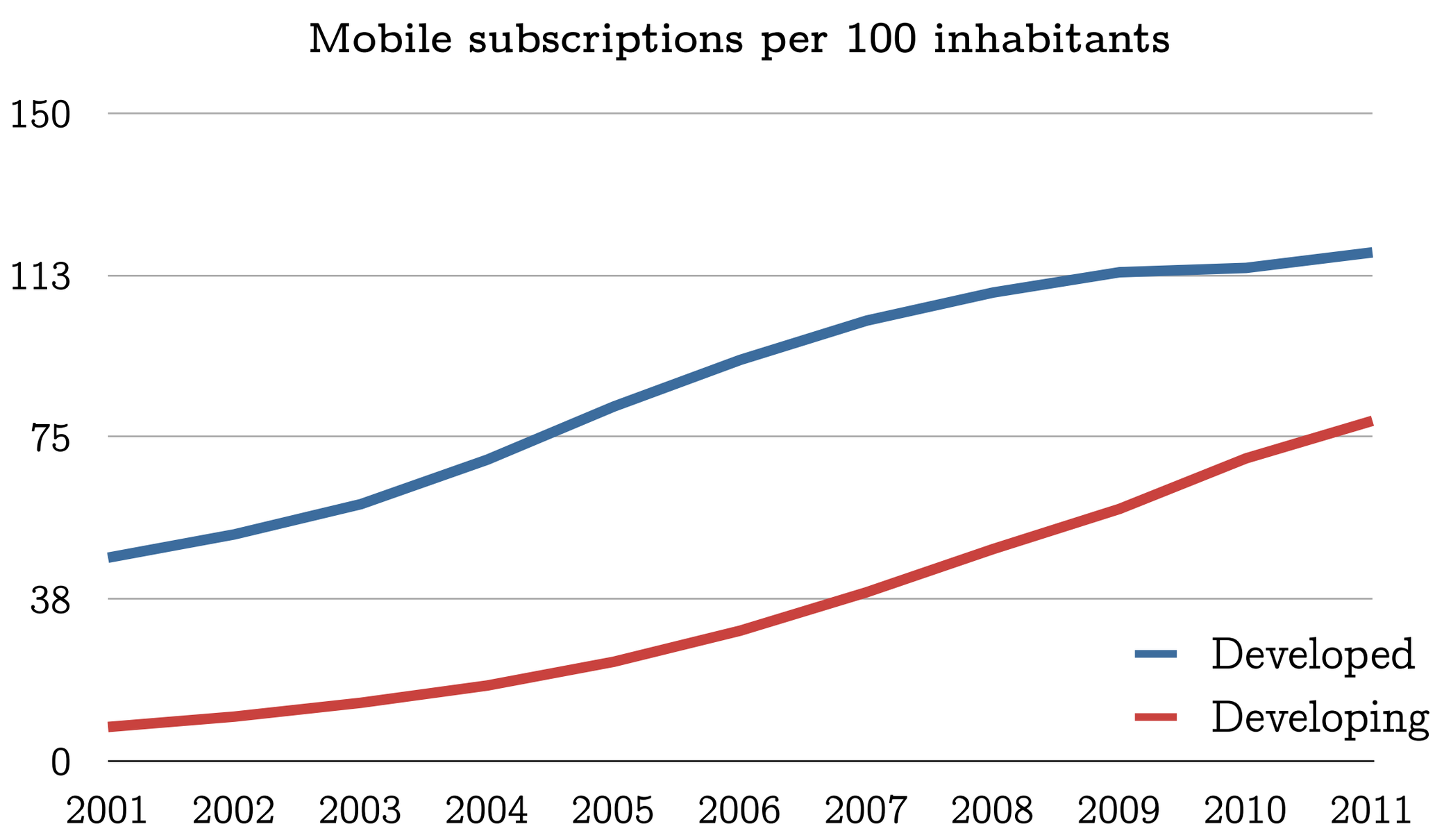
this is work that is done in very deep collaboration with win ribeka and martin were. win and martin work with regenstrief institute in indianapolis.

tapan parikh and gaetano borriello are my academic advisors. tap is at ischool in berkeley and gaetano in cs at uw.

i should note that we published a paper at ictd2012 with a lot more detail than i can get into here, so i'll give you links to that at the end of the talk.

so let's get started, and oh, please feel free to ask questions at any point.

26% of Kenyans have Internet with 98% using cell for access.



quick ice-breaker. can anyone tell me what this graph is?

the red curve is developing countries and the blue curve is developed countries. and this is over time. i'll give you a hint. it has to do with mobile phones.

so it's mobile subscriptions per 100 inhabitants and the thing to take away is that there is incredible growth in developing countries.

so that's amazing right? and with this growth of cell usage has come a growth in internet usage.

let's take kenya as an example.

currently 26% of kenyans have internet access. and 98% of those people get online through the cell networks -- so either on their phone or using a usb dongle.

and these aren't always feature phones. in kenya, the price of the basic smartphone (the android ideos) is about $80-90. and it sells well at that price with some 350k buyers.

so the punchline here is that there is growing internet access and smartphone usage in sub-saharan africa. and on that infrastructure we can build systems that increase the efficiency of healthcare.

let me give you an example...

HCT program identifies patients who need care

a few years ago, i learned about a large hospital network in kenya with a home-based counseling and testing program.

in the program, community health workers go house to house and identify patients who need care (hiv positive unaware of status, pregnant women not on antenatal care, vulnerable children, patients at risk for tb, etc).

historically, the process had been done on paper and pdas. and while it worked, it was slow and inefficient.

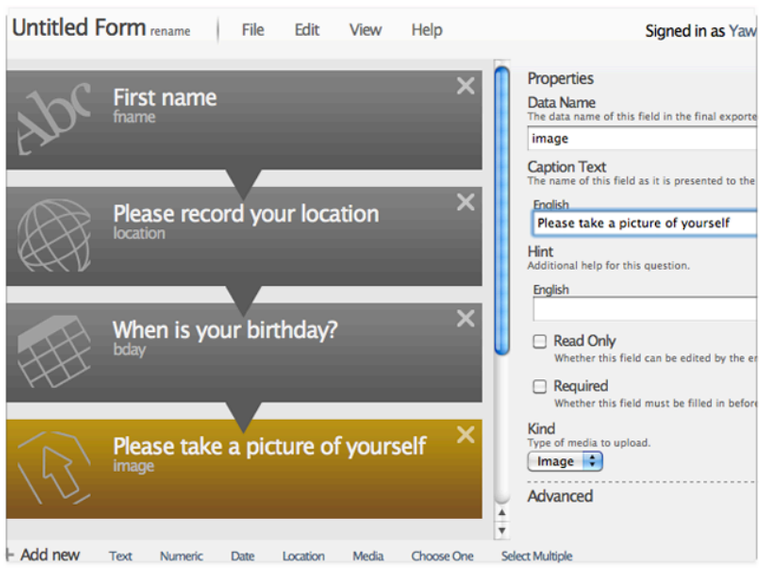
for example, to capture gps coordinates, they would power up these external gpses to record location, then transcribe that result twice into a pda with a stylus. it was error prone and took a lot of training. it worked, but was inefficient.

around that same time i learned about the hct program, i had just started work on a open source toolkit to address these kinds of efficiency gaps with data collection.

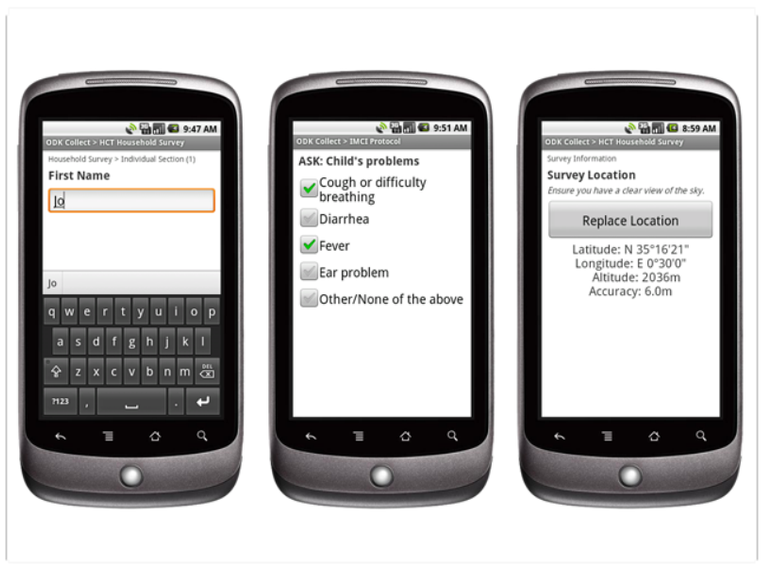
the toolkit is called open data kit.

Open Data Kit uses phones and servers for data collection

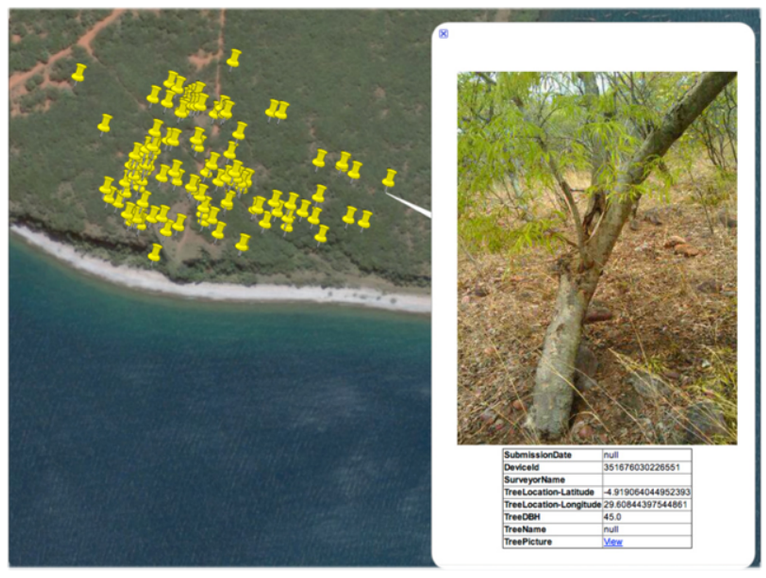
1. Build form



2. Collect data



3. Aggregate results



Hartung et al. Open Data Kit: Tools to Build Information Services for Developing Regions. ICTD, 2010.

open data kit, or odk, uses smartphones and cloud servers to make data collection more efficient.

it's designed to work well in developing regions and to use odk, there are three big steps.

first you build a form -- these can be representations of your standard paper form or the protocol you want a user to follow.

then you use it to collect your data on the phone,

and then you can aggregate the results on a server.

the tools have tens of thousands of users around the world, and it does a lot more than that, but those are the highlights.

let's take a deeper dive into the mobile client.

ODK Collect is a mobile application for form filling

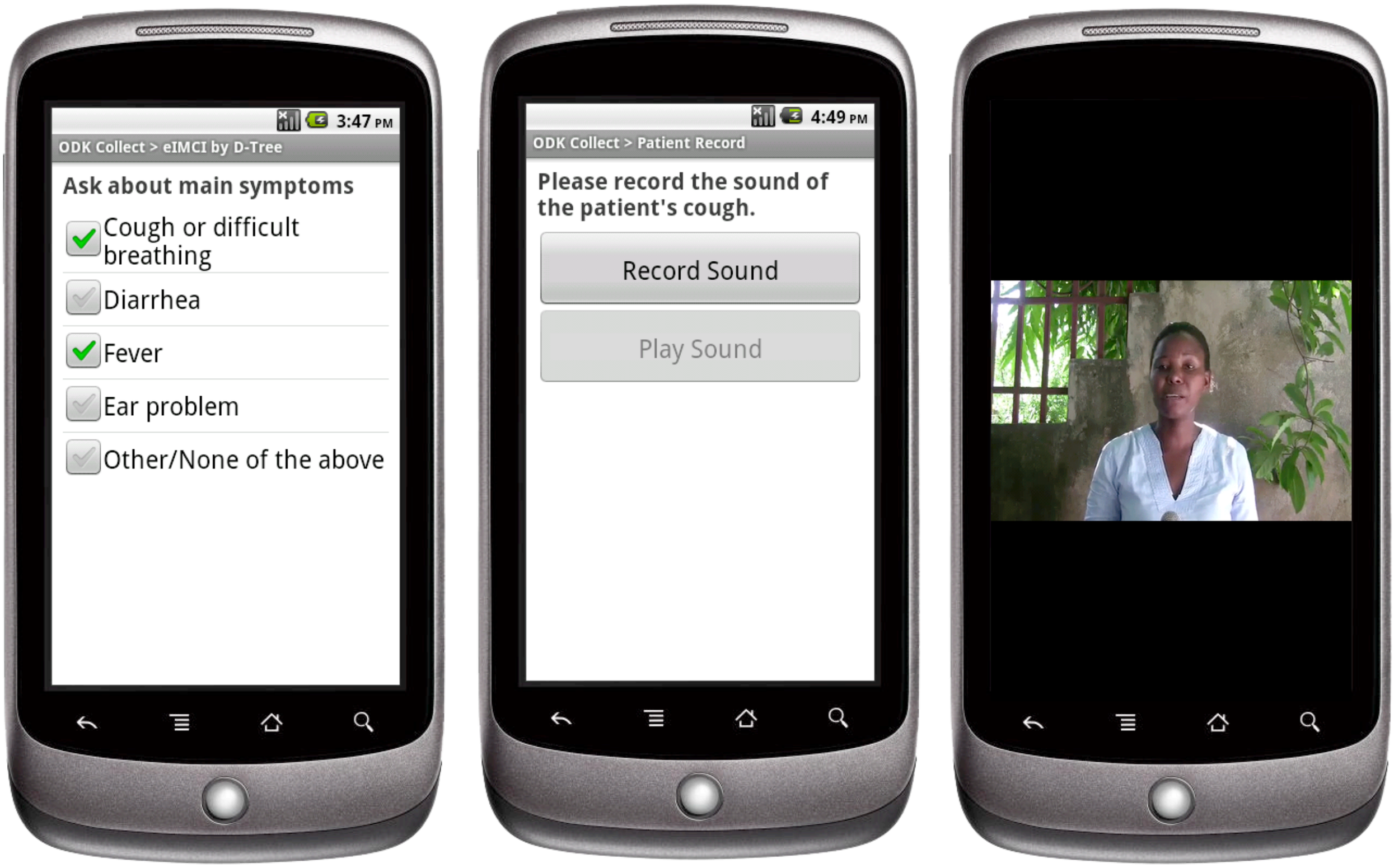
odk collect is the mobile tool and it runs on any android device.

when you give it the form you've designed, the device then walks you through it step-by-step.

so you can could do things like collecting names. and dates. and for all prompts, you can add constraints, so for example, birthdates can't have dates in the future.

and things that are hard with the pda (like gps), you can do in a single click.

Powerful forms with languages, logic and multimedia



the forms themselves are really powerful. so here is an example of imci in swahili.

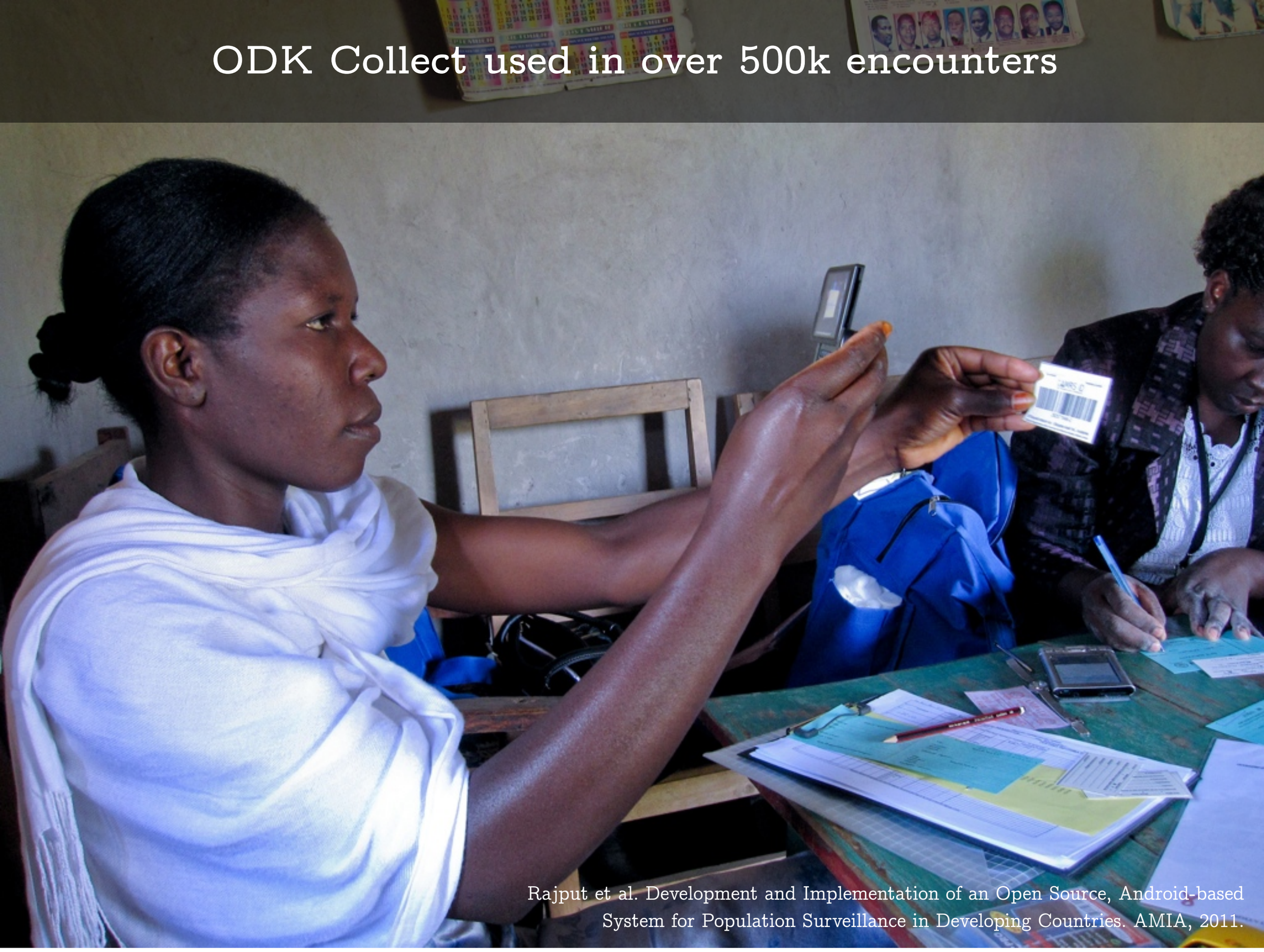
imci is the integrated management of childhood illnesses. it's basically a triage protocol for children under five.

my swahili is weak, so let's switch to english. with odk collect you can do this on the fly.

and if i enter that the child is coughing and has a fever, in the next screen, i can record the sound of the cough and then i can show the mother a video about how to treat fever.

so there is this collection of data, but also a delivery of information using complex logic. any data i gather can be stored offline and then be sent off to a server.

so the hct program encoded their protocol as a form kind of like this and deployed it. that was in early 2010.



since then 300 hct workers have visited over half a million individuals and tested 350k for hiv.

this picture shows one of those workers using the barcode scanner on the phone to identify a patient.

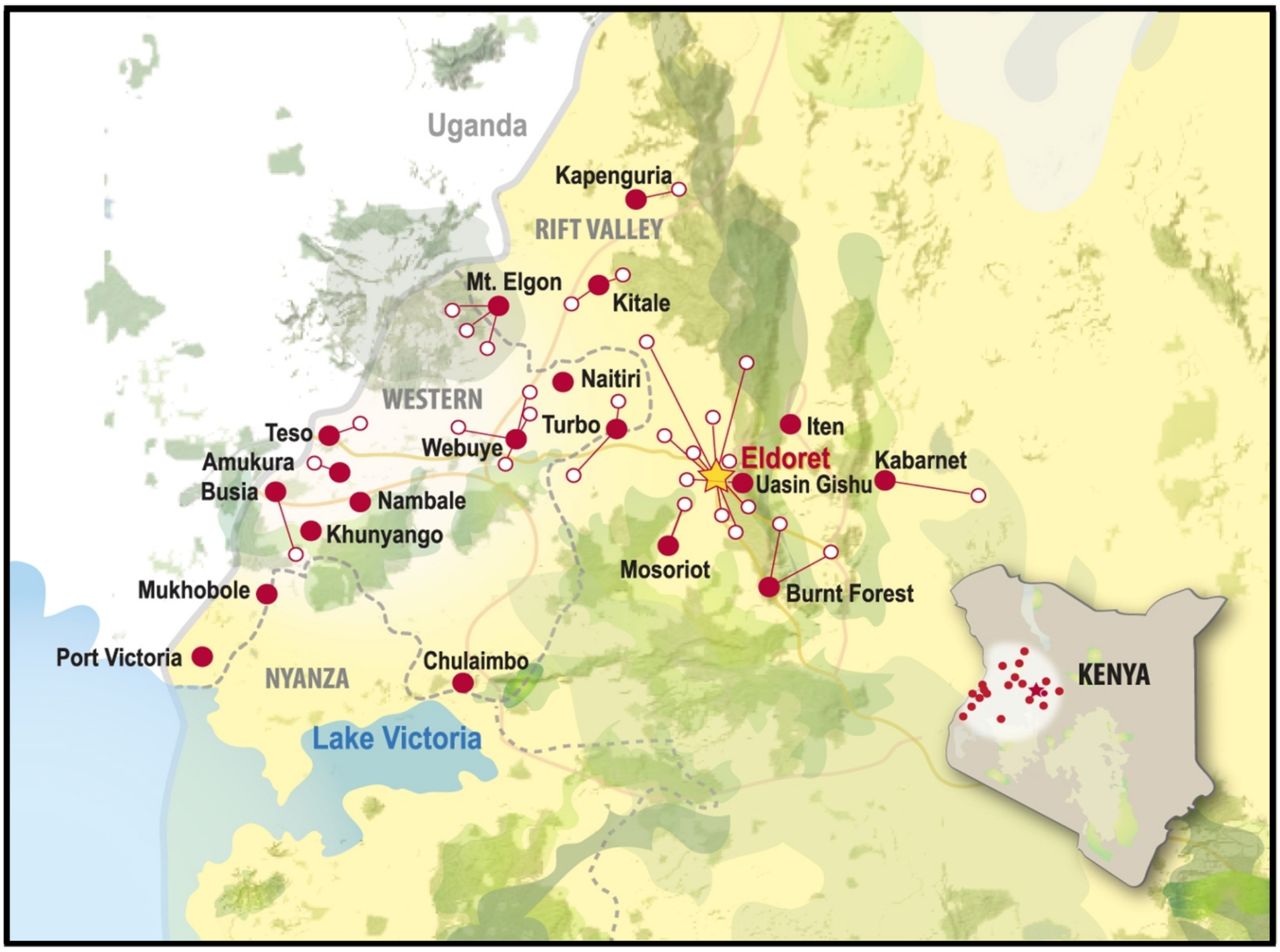
they found the system easy to use and allowed them to collect higher quality data. it was also cheaper and faster than their previous pda-based and pen and paper systems.

and speed matters because earlier reporting which means earlier treatment.

so again here is this hct program that basically works on paper and pda, but is now more efficient through the use of technology. this is a theme that we'll revisit.

i've been a little coy about the organization that did this hct program. any guesses who it is? a large hospital network in kenya?

AMPATH's catchment area has over 2 million individuals



it's ampath. let me tell you a bit about ampath...

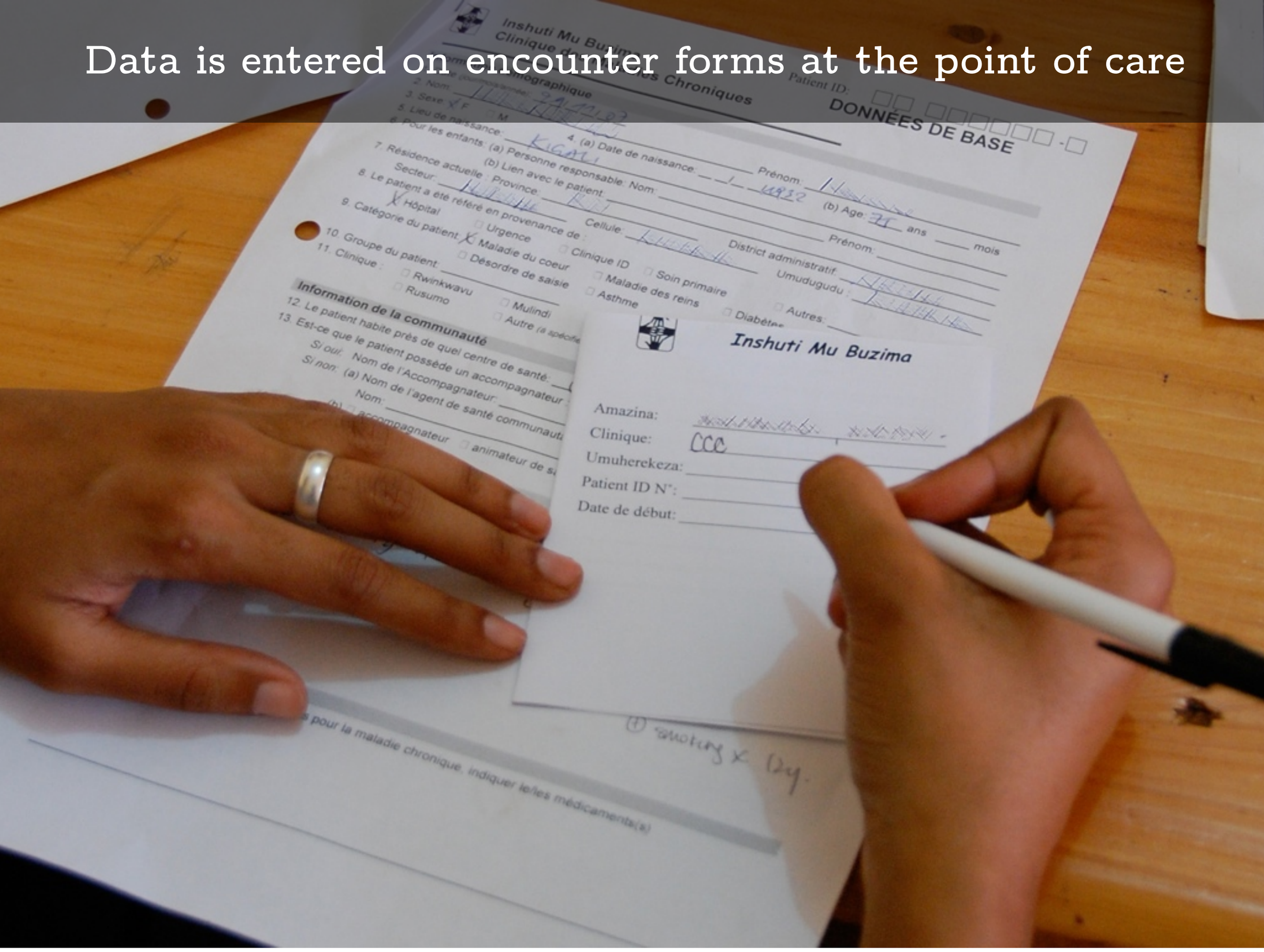
usaid-ampath is the one of the largest hiv treatment programs in sub-saharan africa and is kenya's most comprehensive initiative to combat the virus.

their catchment area has some 2 million people and the program provides care to more than 130,000 active HIV patients through 26 parent and 26 satellite clinics. eldoret, which you can see in the middle, is their main location.

when you get to this size, being efficient is really important and that's again, is where technology can play a key role.

with the success of smartphones in hct, i went back to ampath looking for more problems, this time at the point of care.

and that's when the idea for a phone-based clinical decision support system was born.

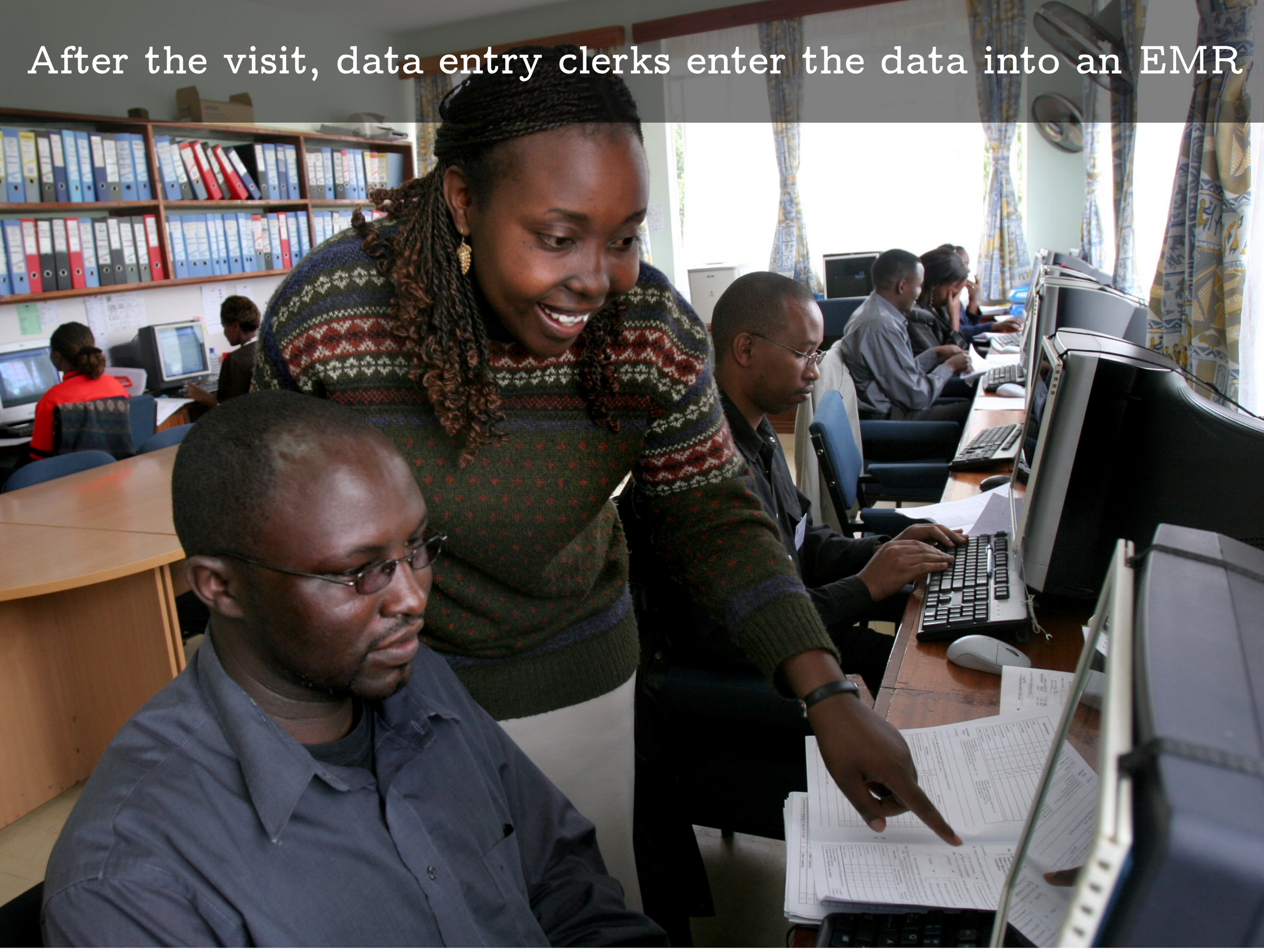


first, a little bit about how patient data is collected.

when a patient comes into a clinic, the clinician fills out a highly structured paper form about the visit.

if the patient is new, they get a really big form. if it is a return visit, it's a very dense two pager. the form goes into the chart, and it is eventually picked up by a data clerk.

After the visit, data entry clerks enter the data into an EMR

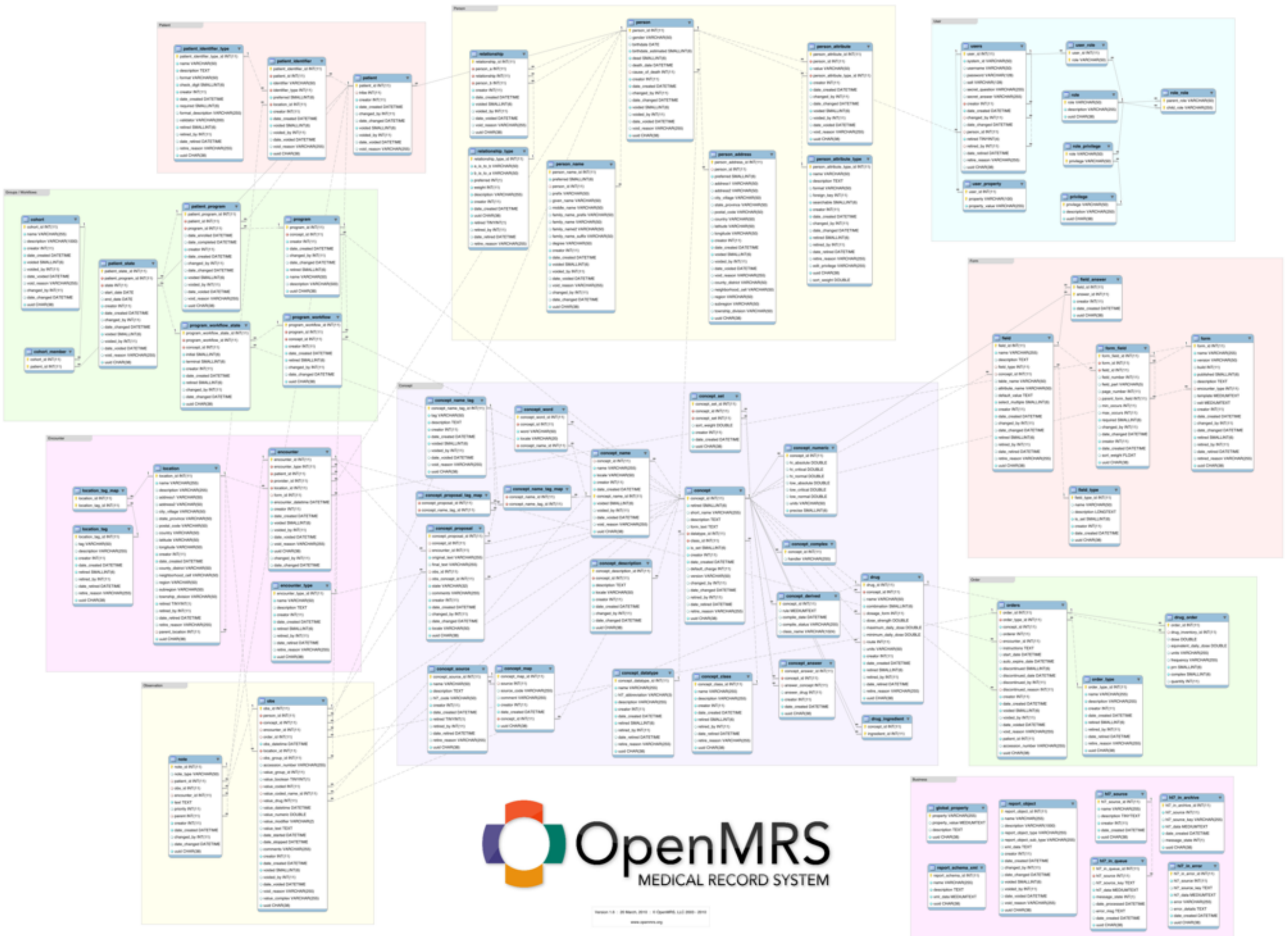


after the patient leaves, the data clerk with minimal computer skills and little medical knowledge enters all visit data from the encounter forms into the medical record system.

a data quality clerk also reviews the encounter data to ensure mistakes are not made.

and when i say a medical records system, i mean it. ampath is unique in that they've really invested in building out a proper medial records system and they are doing it at scale.

Patient data is stored in a highly-structured EMR



the data is stored in openmrs, an open-source electronic medical record system widely used in resource-limited settings. if you aren't familiar with openmrs, you should check it out.

anyway, instead of relying on free-text, patient data (e.g., demographics, problems, diagnoses, medications, labs) in openmrs primarily stored as coded concepts for easy search and analysis.

and as you can see in the diagram, it's a got an extensive and highly structured data model.

ampath has a central openmrs server but also has satellite servers that get synchronized to central (either over a network connection or using usb).

Patient data is used in reports, but not often in patient care

despite all the patient data that is stored in openmrs, it’s not directly used at the point of care where it really matters.

and there are a lots of reasons for this which i won’t get into, but whatever the reasons, it tends to go into reports to funders and other higher level stakeholders.

Overworked clinicians in busy clinics can lead to poor care

this is unfortunate because as most of you know, healthcare in developing countries is primarily delivered by overworked clinicians who might benefit from this assistance.

add to that the fact that these clinics (especially the remote ones) are very busy and under-resourced.

just for some perspective on how under-resourced, the us has one clinician per 400, kenya has one clinician per 7,000.

so how do clinicians at ampath get patient data?

Encounter forms are returned to patient charts

usually from a place like this. this is a well cataloged and organized repository.

when the data on encounter forms have been entered, they are returned to the patient's chart, and are made available to the clinician during the patient's return visit.

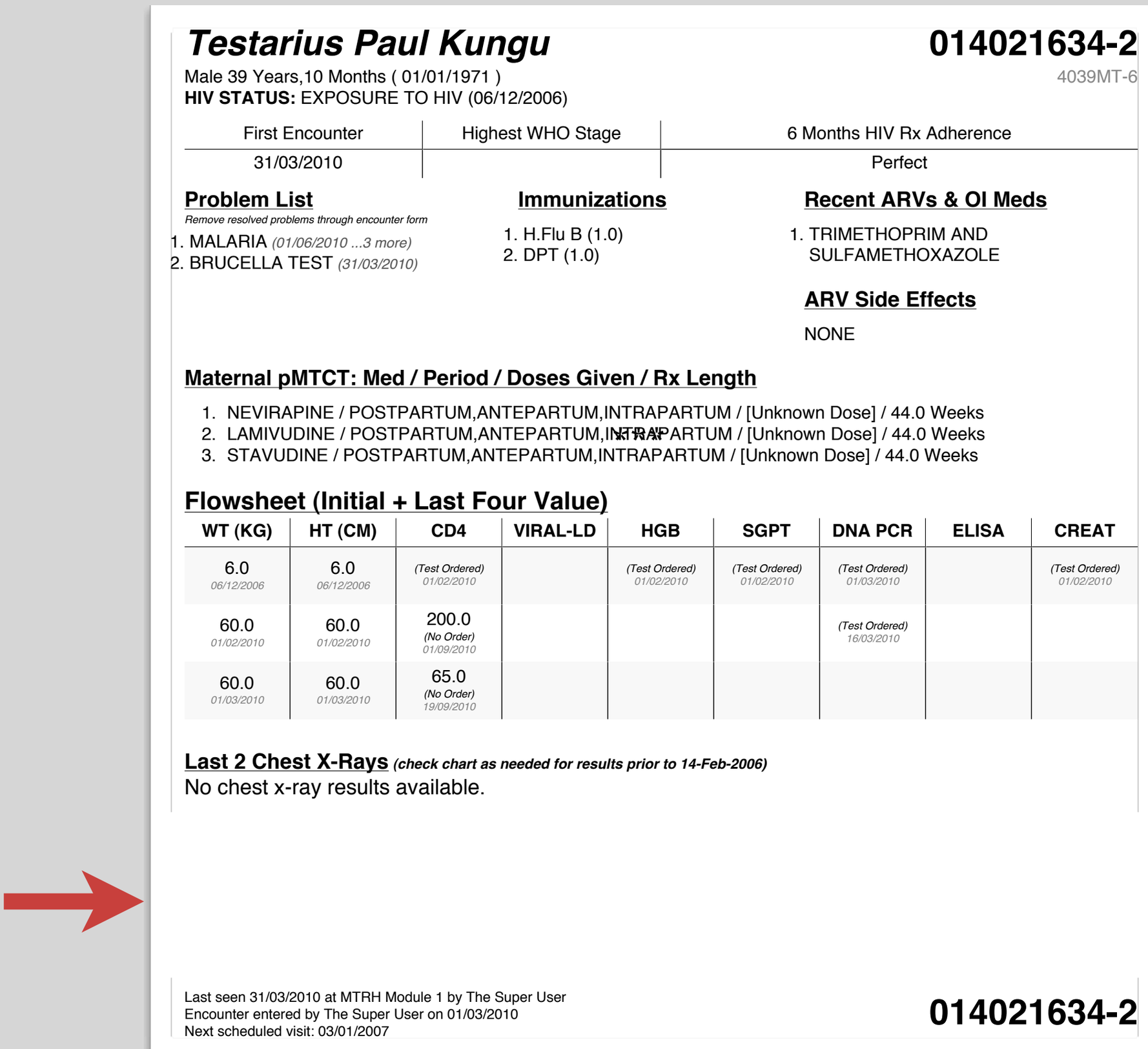
for small clinics seeing a few patients, this might be manageable, but when you get to ampath's size, this system isn't sustainable.

this is especially important if you are treating hiv or other chronic care patients who generate a lot of paper records.

ampath understands the problems with this approach -- if you are looking over lots of handwritten encounter forms, it's pretty easy to miss a lab value or misread something. and so over the last few years, they been working really hard to bring patient data paired with decision support to the point of care.

one of the tools being used is printed clinical summaries. this is work that martin were has been responsible for.

Summaries and reminder are good decision support tools



Testarius Paul Kungu **014021634-2**

Male 39 Years,10 Months (01/01/1971) 4039MT-6
HIV STATUS: EXPOSURE TO HIV (06/12/2006)

First Encounter	Highest WHO Stage	6 Months HIV Rx Adherence
31/03/2010		Perfect

Problem List
Remove resolved problems through encounter form
1. MALARIA *(01/06/2010 ...3 more)*
2. BRUCELLA TEST *(31/03/2010)*

Immunizations
1. H.Flu B (1.0)
2. DPT (1.0)

Recent ARVs & OI Meds
1. TRIMETHOPRIM AND SULFAMETHOXAZOLE

ARV Side Effects
NONE

Maternal pMTCT: Med / Period / Doses Given / Rx Length
1. NEVIRAPINE / POSTPARTUM,ANTEPARTUM,INTRAPARTUM / [Unknown Dose] / 44.0 Weeks
2. LAMIVUDINE / POSTPARTUM,ANTEPARTUM,INTRAPARTUM / [Unknown Dose] / 44.0 Weeks
3. STAVUDINE / POSTPARTUM,ANTEPARTUM,INTRAPARTUM / [Unknown Dose] / 44.0 Weeks

Flowsheet (Initial + Last Four Value)

WT (KG)	HT (CM)	CD4	VIRAL-LD	HGB	SGPT	DNA PCR	ELISA	CREAT
6.0 *06/12/2006*	6.0 *06/12/2006*	*(Test Ordered)* *01/02/2010*		*(Test Ordered)* *01/02/2010*	*(Test Ordered)* *01/02/2010*	*(Test Ordered)* *01/03/2010*		*(Test Ordered)* *01/02/2010*
60.0 *01/02/2010*	60.0 *01/02/2010*	200.0 *(No Order)* *01/09/2010*				*(Test Ordered)* *16/03/2010*		
60.0 *01/03/2010*	60.0 *01/03/2010*	65.0 *(No Order)* *19/09/2010*						

Last 2 Chest X-Rays ***(check chart as needed for results prior to 14-Feb-2006)***
No chest x-ray results available.

Last seen 31/03/2010 at MTRH Module 1 by The Super User
Encounter entered by The Super User on 01/03/2010
Next scheduled visit: 03/01/2007

014021634-2

so thanks to martin, ampath now has paper-based clinical summaries for patients. it's one page sheet that is generated from the electronic medical record system and put in all the patient charts when the patient presents.

it gives a nice overview of all the relevant patient data and solves the problem of having to find and go through paper records when you see a patient. the paper summaries are in all sites and are well-liked.

there are a variety of summaries -- adult/peds hiv, pmtct, antenatal and primary care.

when ampath analyzed the data after they rolled out that system for adult hiv patients, they found out that half of the patient visits with summaries were failing to confirm to the cd4 lab ordering schedule that the ampath/moh say is good care.

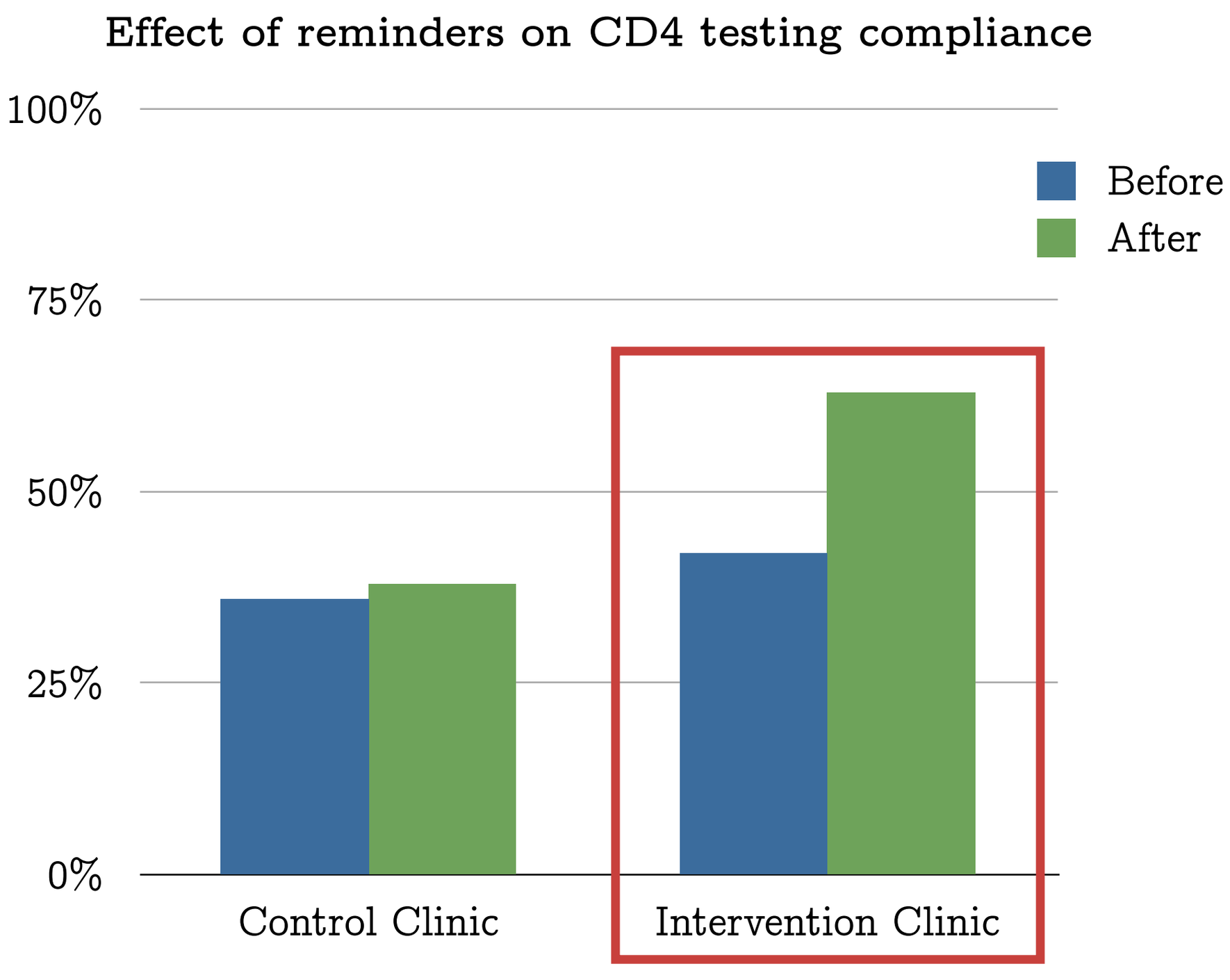
cd4 is a basic and very critical hiv indicator, and if you don't get it measured regularly, you really can't tell how a patient is responding to arv drugs.

to address this problem, ampath decided to add automatically generated reminders about the lab ordering schedule to the summary. if the system notices you are late for a cd4 test (or any other important lab), it prints a friendly reminder.

now these are patient specific and they build on more than just one lab value. they look at the entire patient record to make decisions. in addition to cd4, there were reminders about overdue labs, start/stop medications, referrals, etc.

so then the question is, can clinical summaries and reminders improve the problem of cd4 ordering schedule that i mentioned earlier.

Reminders increase compliance with care guidelines



Were et al. Evaluation of computer-generated reminders to improve CD4 laboratory monitoring in sub-Saharan Africa. JAMIA, 2011.

ampath ran a study measure the effect of reminders on cd4 testing compliance. this is work published at jamia.

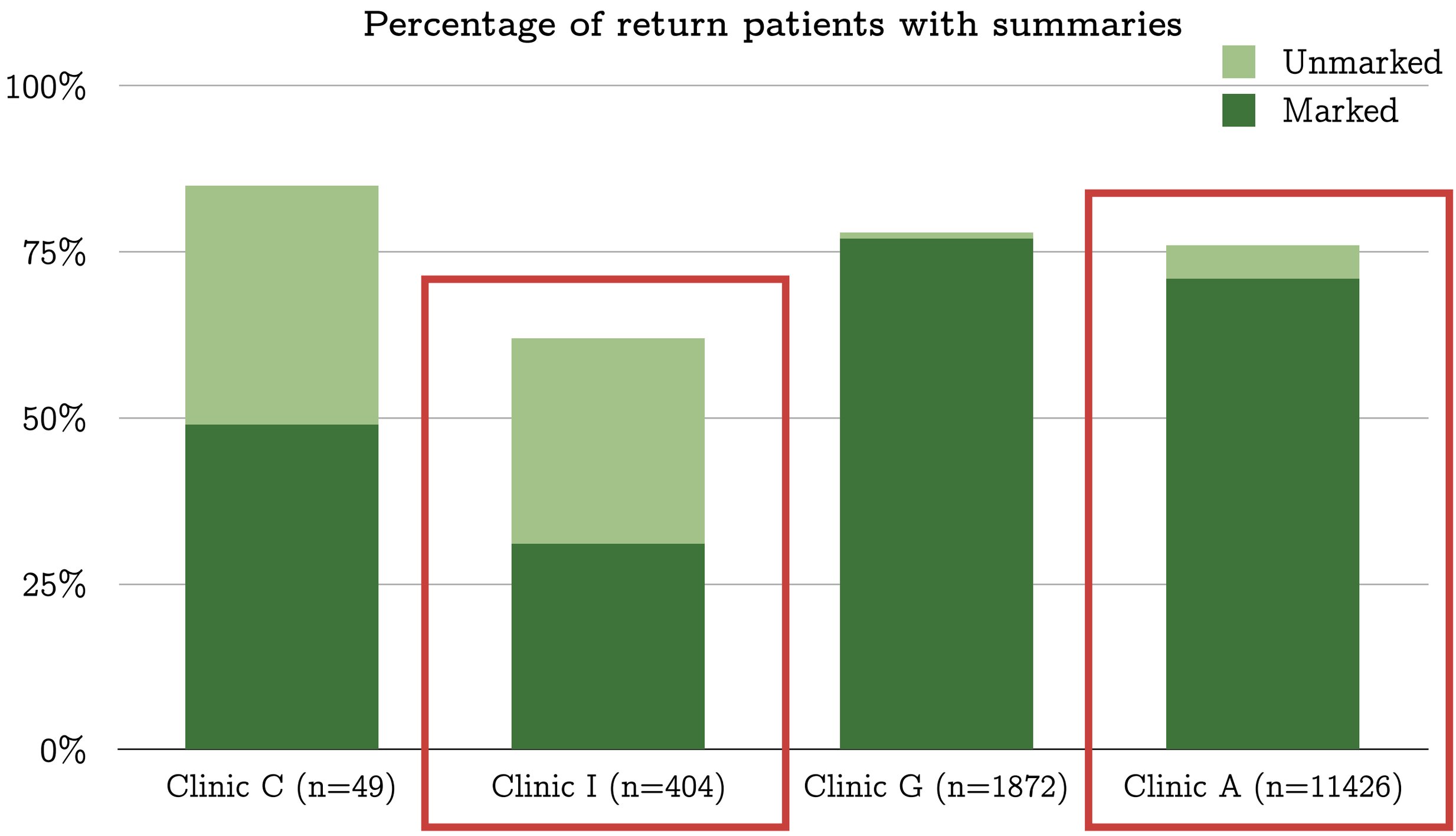
on the y-axis, is compliance. the more compliance the better.

on the x are the two arms of the study -- the control and the intervention. you don't necessarily need 100% compliance, but given that these are basic indicators they should be pretty high.

so in the intervention, you see that before reminders, compliance is around 42%. add the reminders and that increases to 63%. this is statistically significant and strongly suggests that better care is being delivered.

great, why not do more of this?

Across AMPATH sites, 20% of patients get no summaries



Anokwa et al. Design of a Phone-Based Clinical Decision Support System for Resource-Limited Settings. ICTD, 2012.

well, it's really hard to get the summaries at the point of care.

let's look at the percentage of return patients with summaries. focus on clinic a first.

marked (dark-green) means the clinician put a physical mark that said they had seen the summary. unmarked (light-green) means there was a summary, but we don't know if the clinician looked at it.

and the gap between the top of the bars and 100% are the patients who didn't have summaries. so in clinic a, 25% of patients didn't get summaries.

you can see that marking rates are worse at the more rural and smaller sites.

so for example in clinic i, half of the summaries aren't marked -- that is, we don't know even if clinicians looked at them.

across 50k visits in 18 sites where we have data and it turns out 20% of visits had no summaries available.

why is this?

the basic problem is that logistics of running the paper system are hard to get right in these settings. it's very failure prone.

take this picture as an example. here is a top down view of a nurses desk next to a computer and a printer.

so the patient sits on the left, the nurse sits on the right.

you see where the problem is?

it's right there in the computer cables.

if the patient is a mother and has some children with her, those kids are going to yank on those cables of the printing computer. even if she has no kids, it's possible that her feet will get caught on those cables and yank something out.

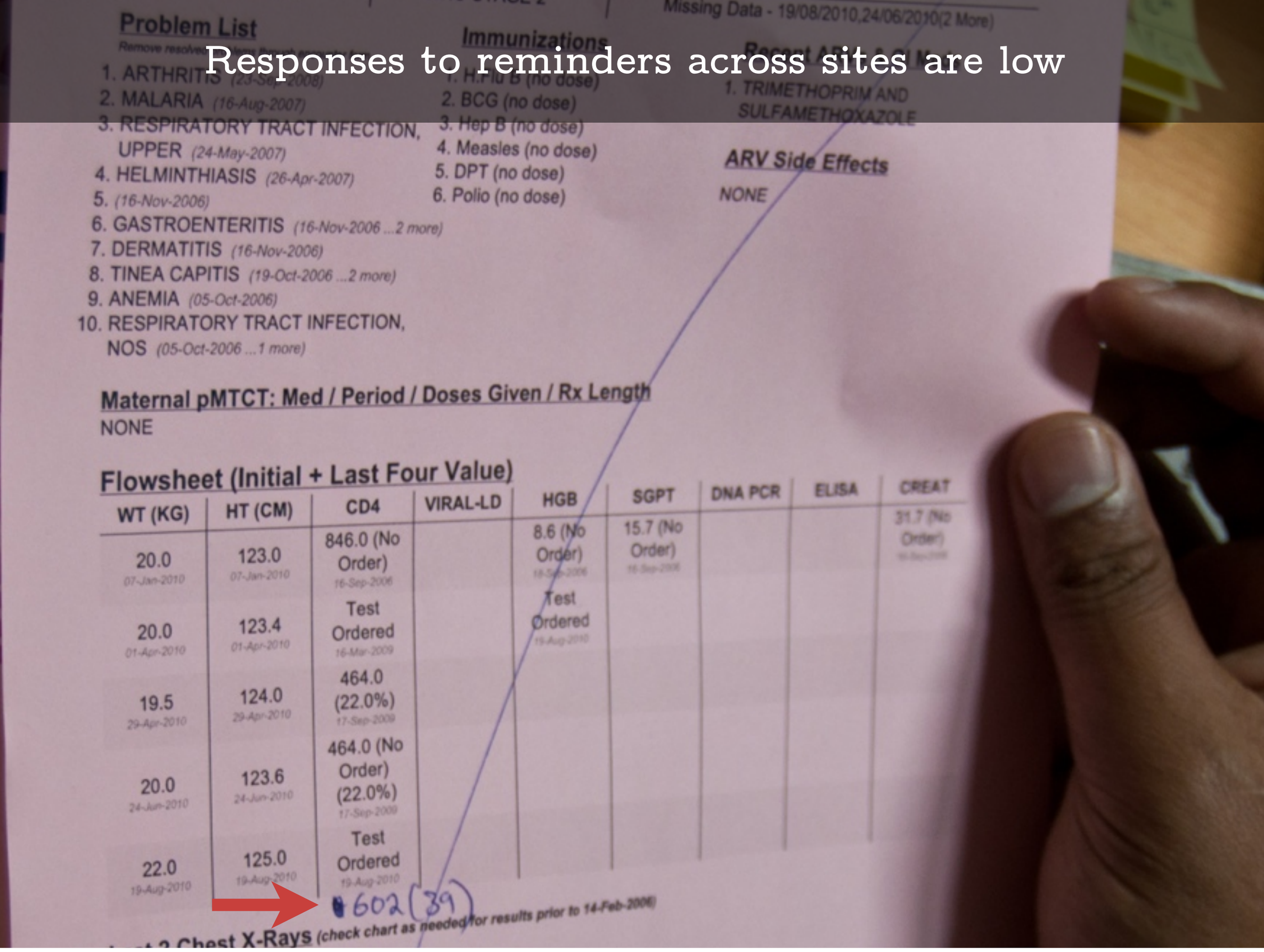
in most places in the world, this wouldn't be a problem.

the reality of ampath is that the nurses won't know what has gone wrong -- printing of summaries will just be broken.

and they won't necessarily tell the supervisor that printing isn't working. and even if they did, that information won't necessarily bubble up to someone who can fix it -- no one wants to get into trouble.

some of this is training, some of it is culture, some is power dynamics, but the bottom line is that the most efficient way to catch these problems is with a more real-time transparent monitoring system.

Responses to reminders across sites are low



and even of the patients that get summaries with reminders, responses to the reminders are very low. in my interviews with clinicians, there were lots of underlying problems.

for example, reminders build on data in the medical record system, so when that data is incorrect, the reminder is also incorrect. when clinicians see a mistake in the summary.

they are supposed to try to correct it on the summary, like this, and send that piece of paper in for data entry.

this is a great idea in theory, but each time you create a new reminder for clinicians to respond to, it exposes a lot of bad data, and that correction process overwhelms the data entry staff and so corrections can take a long time.

clinicians are human and so after they see the mistake and correct it three or four times, they end up getting irritated and loosing faith in the system.

and so ampath staffers have to continuously go find these clinicians and do their best to enforce or facilitate responses to reminders. again, that's inefficient.

so these are the kinds of problems that inspired our work on odk clinic. and to guide our design, we created a few design principles.

Principles that guided design of ODK Clinic

- Support a variety of summary types
- Assume unreliable or disconnected servers
- Use large, minimal, and consistent widgets
- Model UI on the existing paper summary
- Discard any functionality that duplicates work

the first principle was to support a variety of summary types. for example, the system should be able to create a summary for a pharmacist with prescribed medications and reminders about drug interactions.

network connections, even internal to ampath are unreliable. we wanted the mobile client to work offline by default and download/upload intelligently. this also helps with making everything as fast as possible for clinicians.

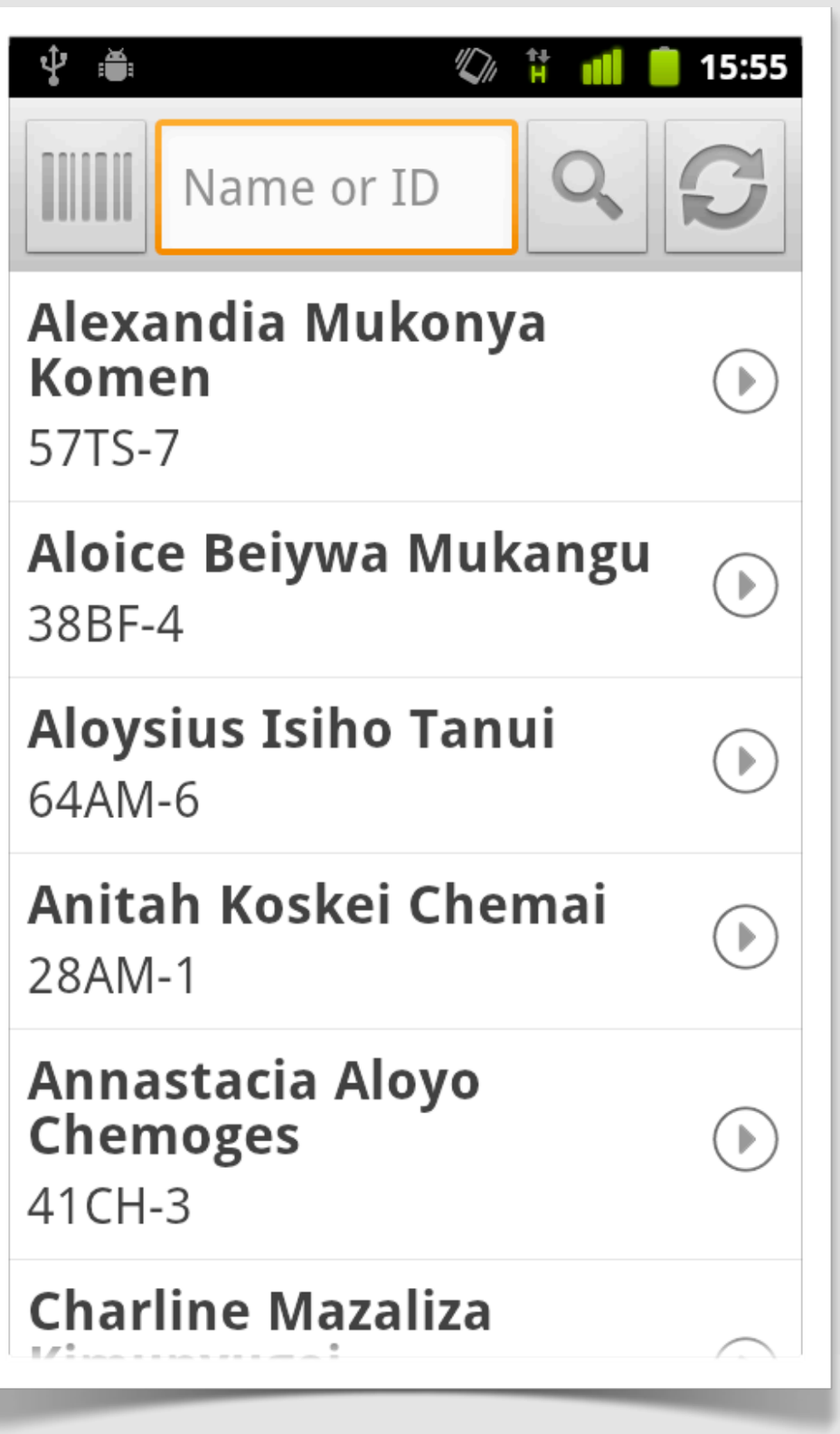
in our work on odk collect, we've learned that a lot of our users have calloused fingers and uncorrected vision. this makes it hard to use a touchscreen -- they need soft fleshly fingers to work. so, we use large, high contrast, and consistent widgets that users can hit. these are pretty standard ui tricks, but it's even more important when you want to drive down training costs.

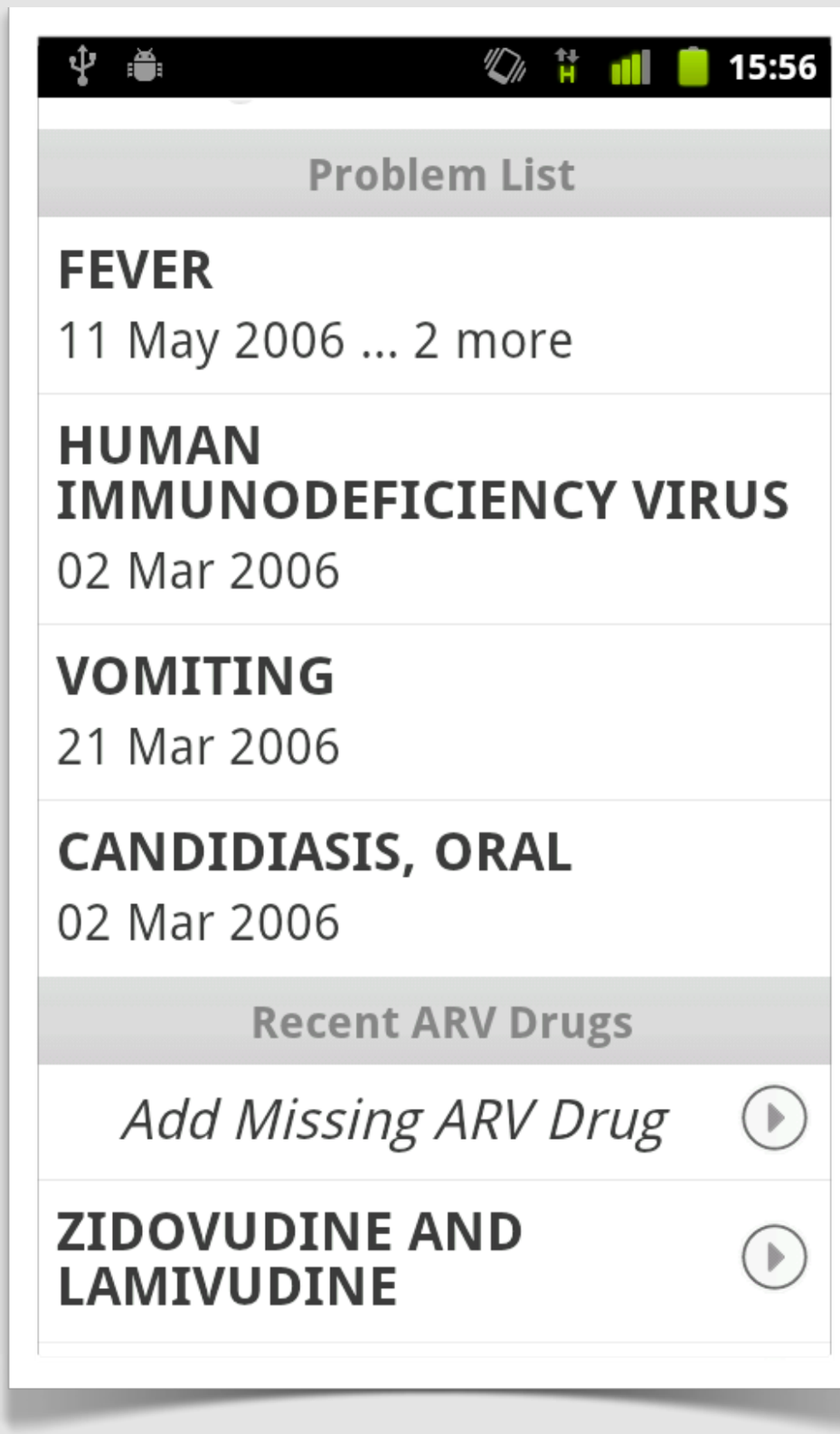
we mirror the paper summary as much as possible. for example, because clinicians are trained on reading lab values in columns, we do not graph lab values. we also only display data that is important to decision-making. as users grow familiar with the phone-based system, we expect this to change.

odk clinic is just for the summary sheet and nothing else and so that's all the functionality we provide. clinicians still have to use the encounter form, even though it could be implemented as a form on the phone with odk collect.

why? well, encounter forms are at the heart of every patient encounter at ampath. changing the process is logistically impractical. instead, ampath sees replacing paper summaries with odk clinic as the first step in understanding how to replace the paper encounter forms with tools like odk collect.

List of patients and individual patient view

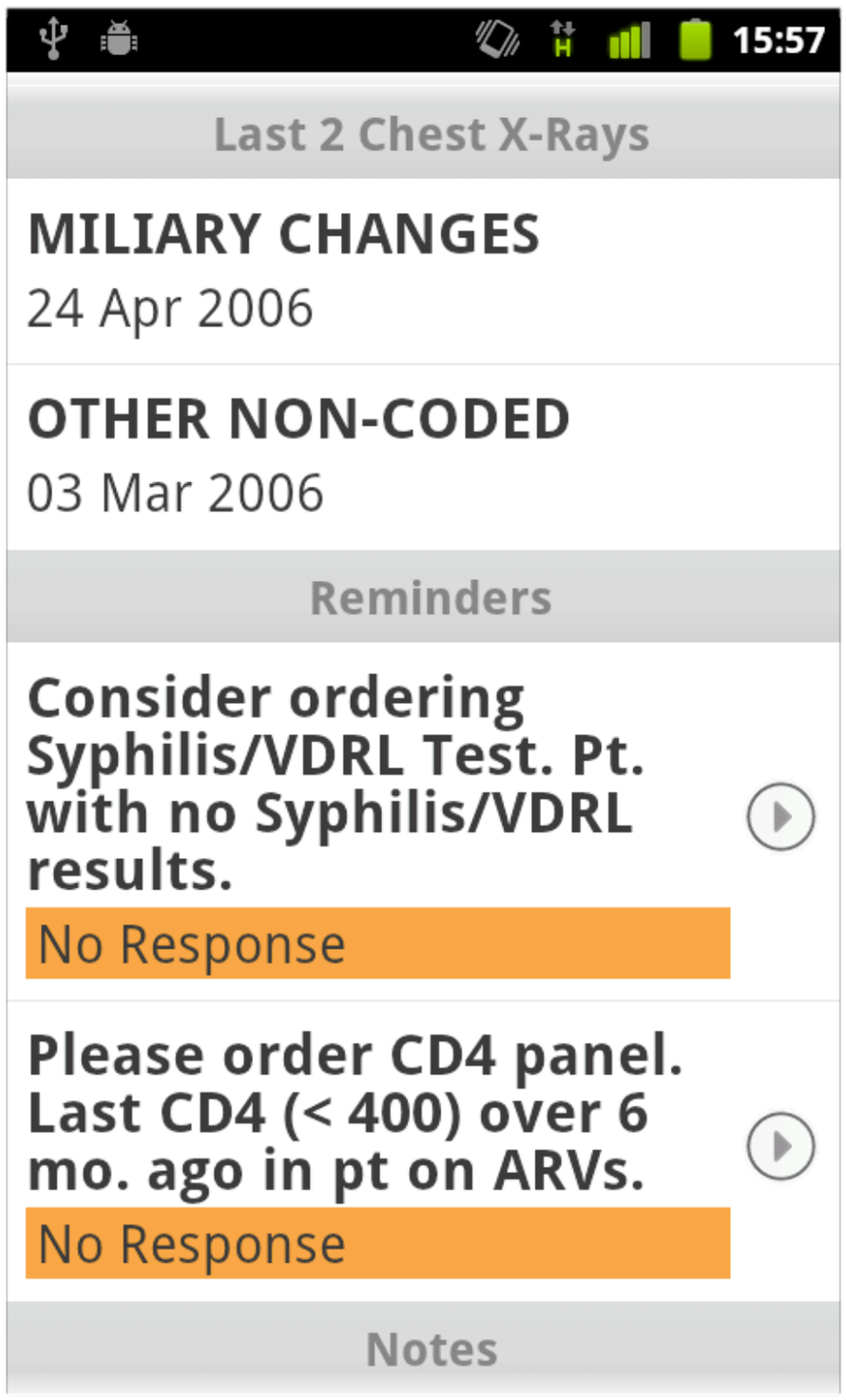


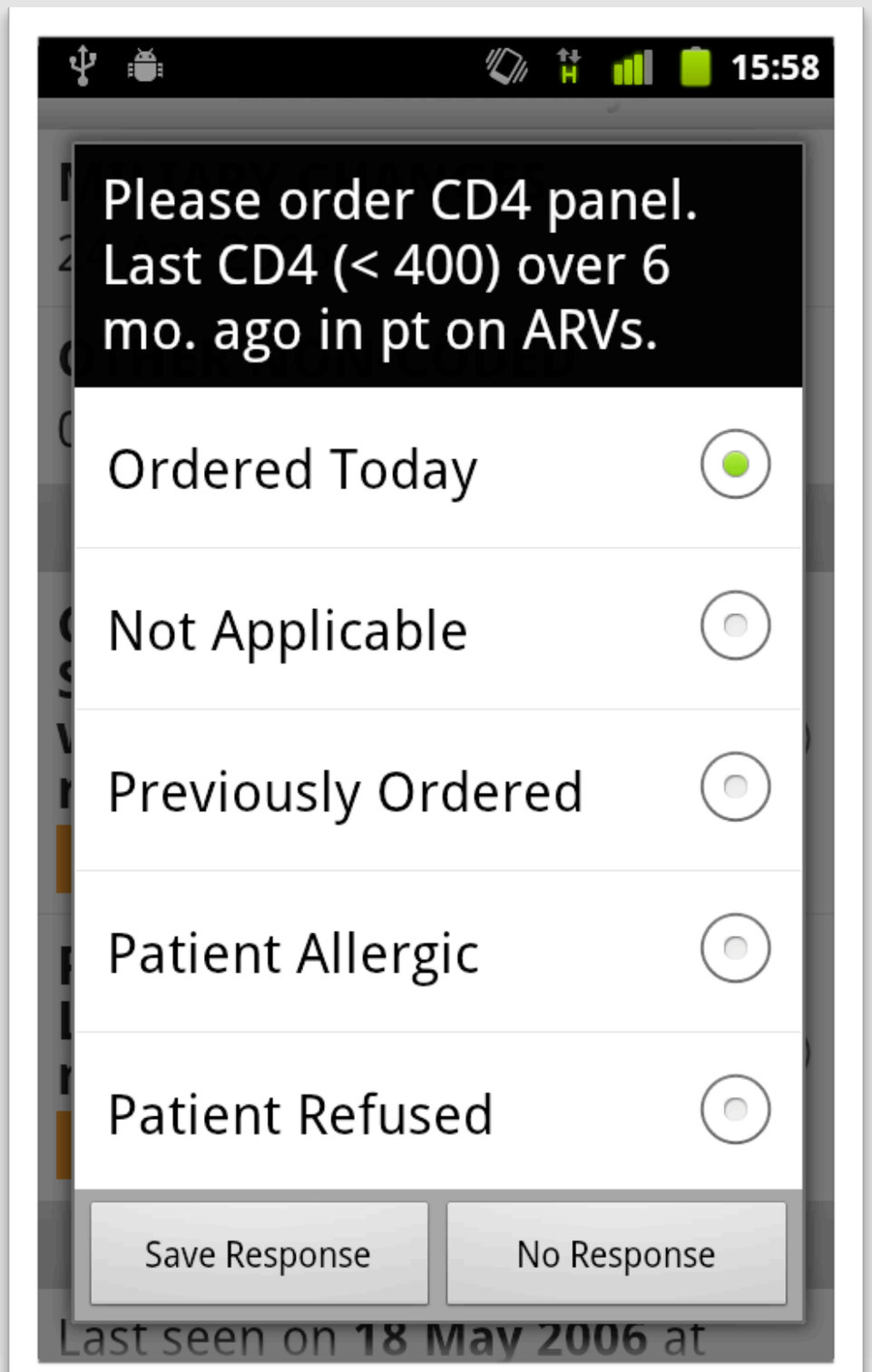


clinicians get a list of patients on the device. these are the patients that are likely to visit a week before and a week from now. usually this is any where from 300-1000 patients, and that usually takes about a minute or two even over bad network connections. once the patient summaries are on the phone, they are available even when the medical record system is down. we can cache lots of patients if necessary.

when a clinician taps on a patient, it loads the summary for that patient. this summary is exactly like the paper summary. it has demographics, problem list, recent drugs, lab values, and reminders.

Inline reminders and reminder responses

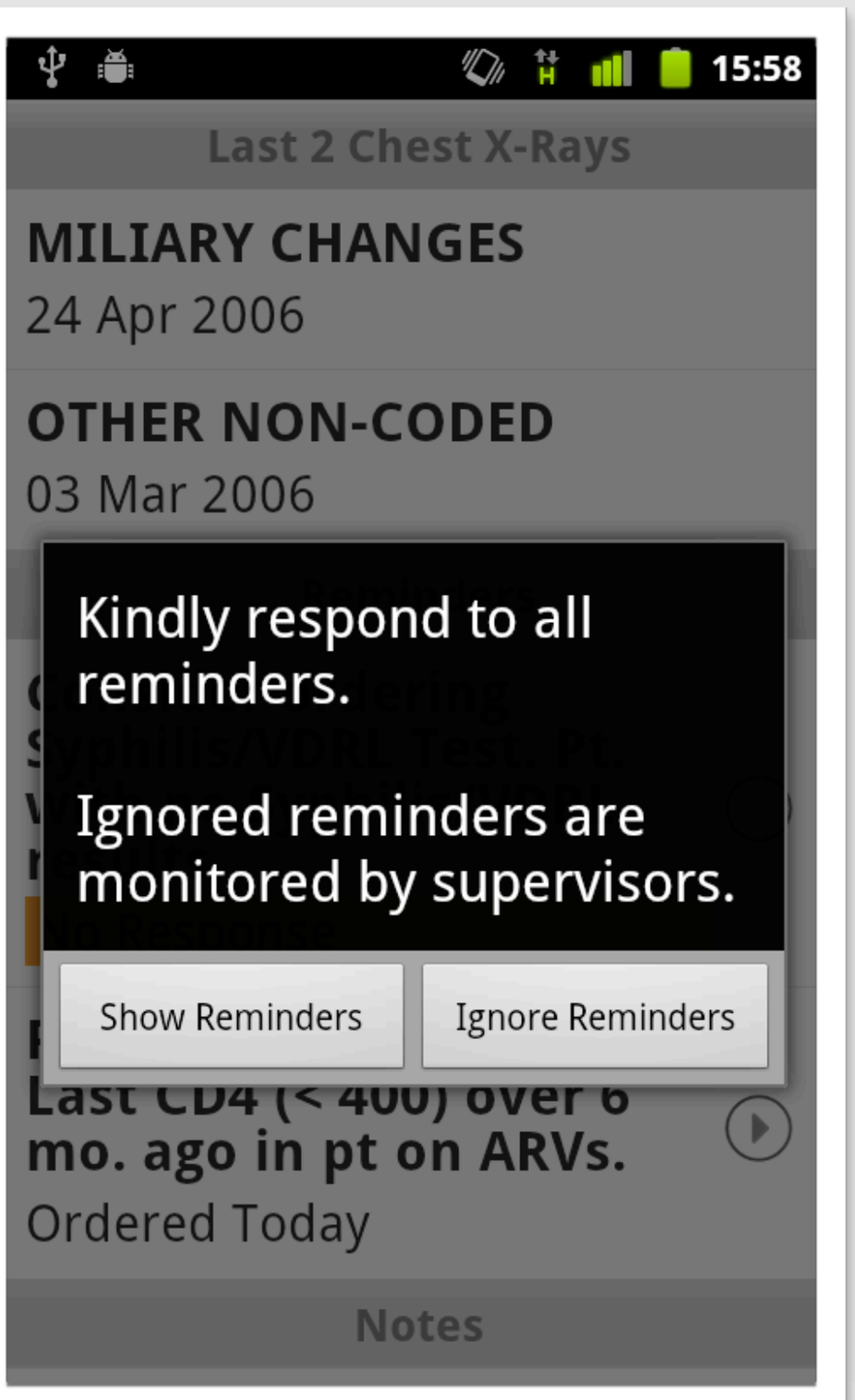


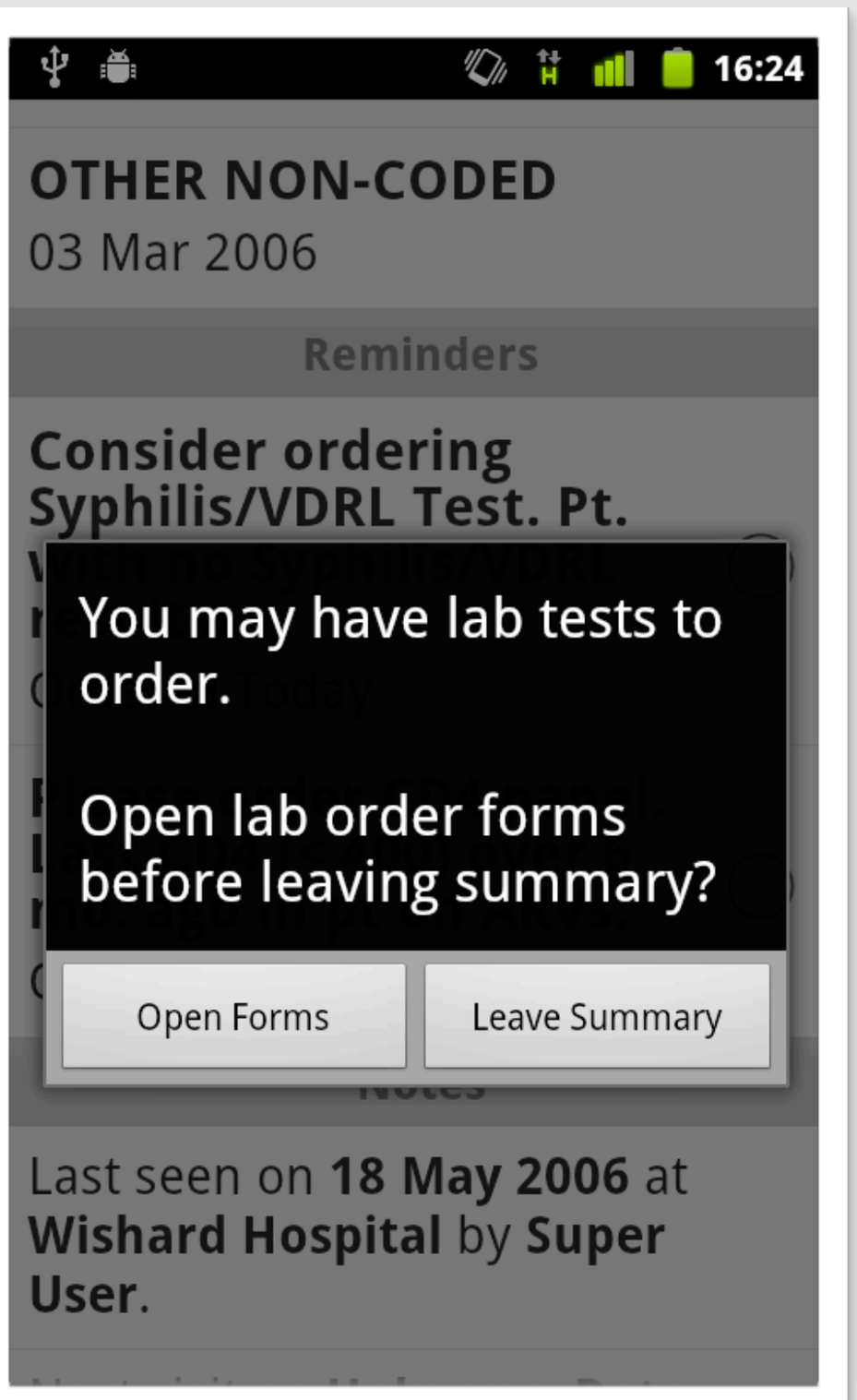


if a clinician scrolls to the bottom of the summary, they can see the reminders. touch on any one and they get the response options -- ordered today, not applicable, previously ordered, patient allergic, patient refused, i disagree, and other.

everything is strongly coded. for example, for previously ordered, clinicians can enter the date they ordered the lab and the value.

Prompts to respond to reminders and for lab orders

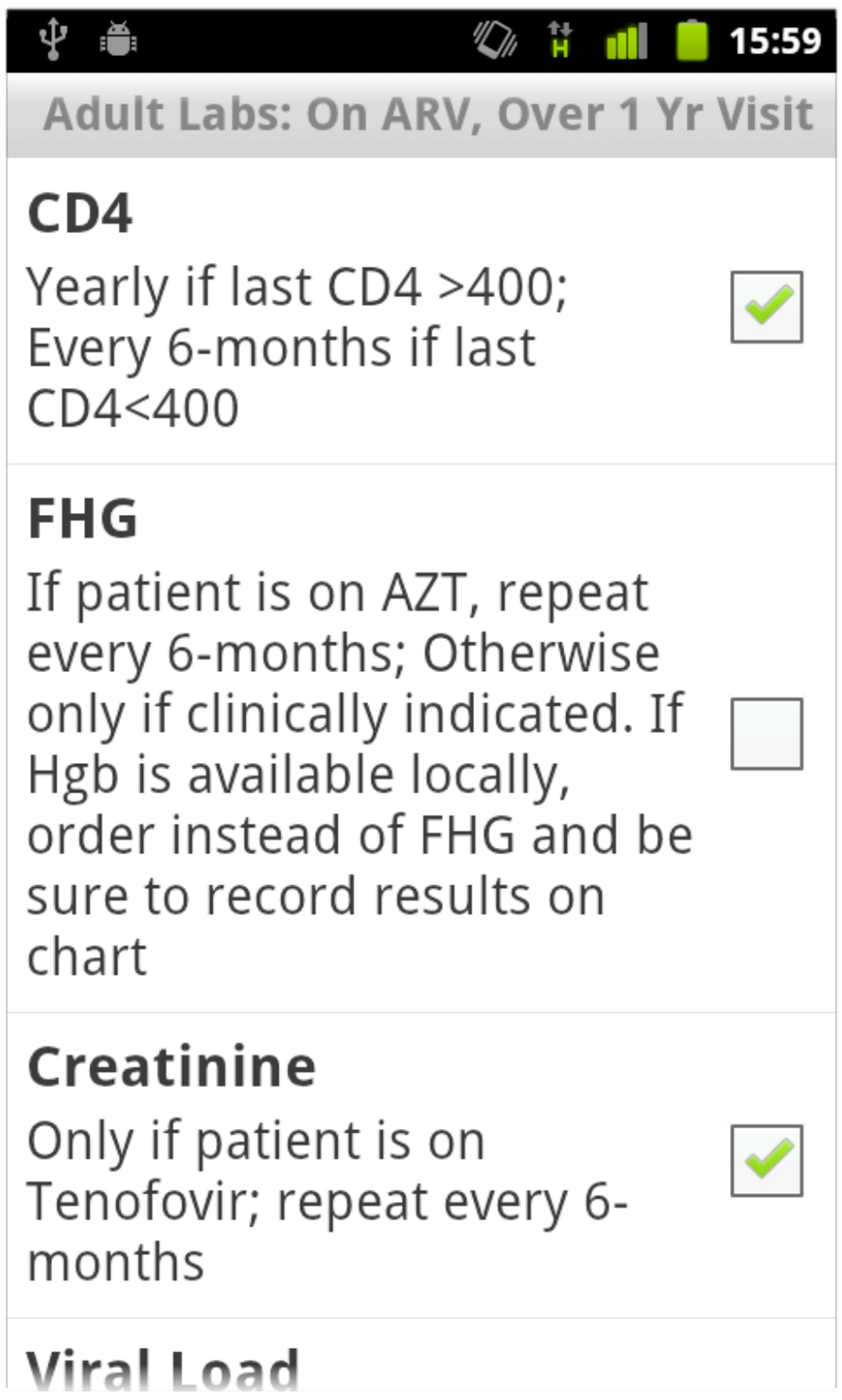


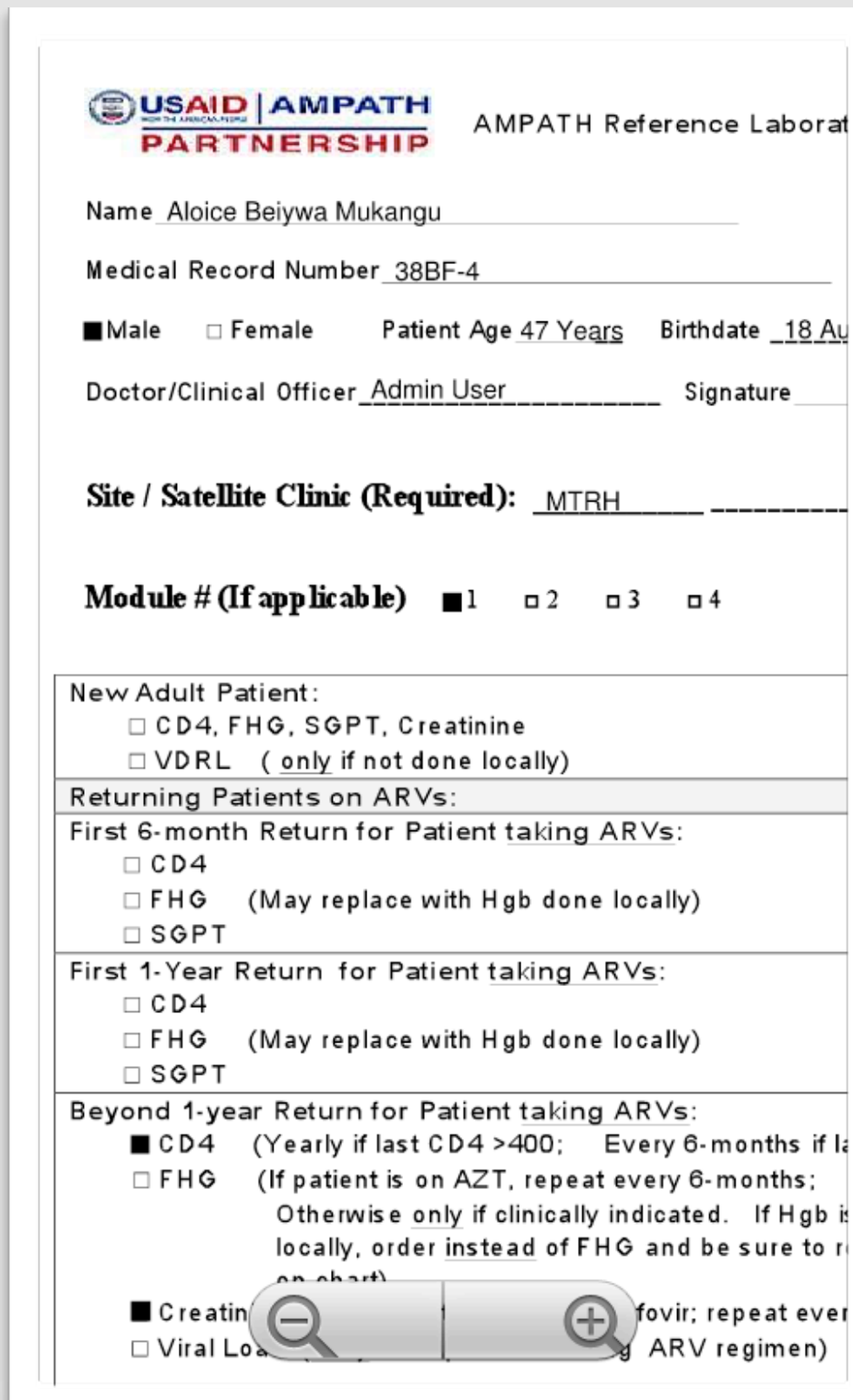


we have prompts throughout the system that are designed around the standard operating procedures..

if a clinician doesn't respond to reminders and tries to exit, they are prompted. if a clinician notes that they want to order a lab test, we prompt about that so they don't forget.

Lab ordering and printing

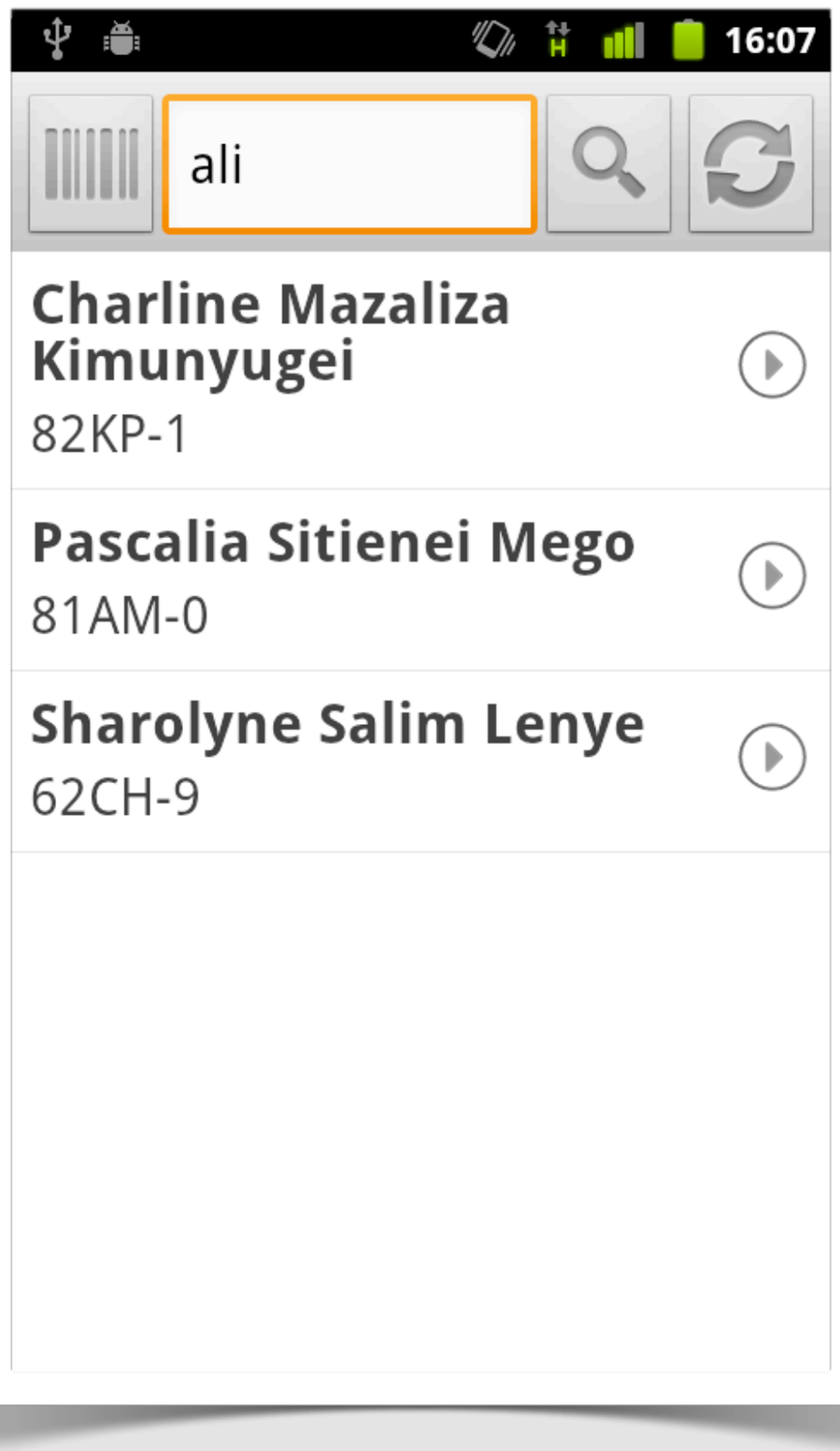


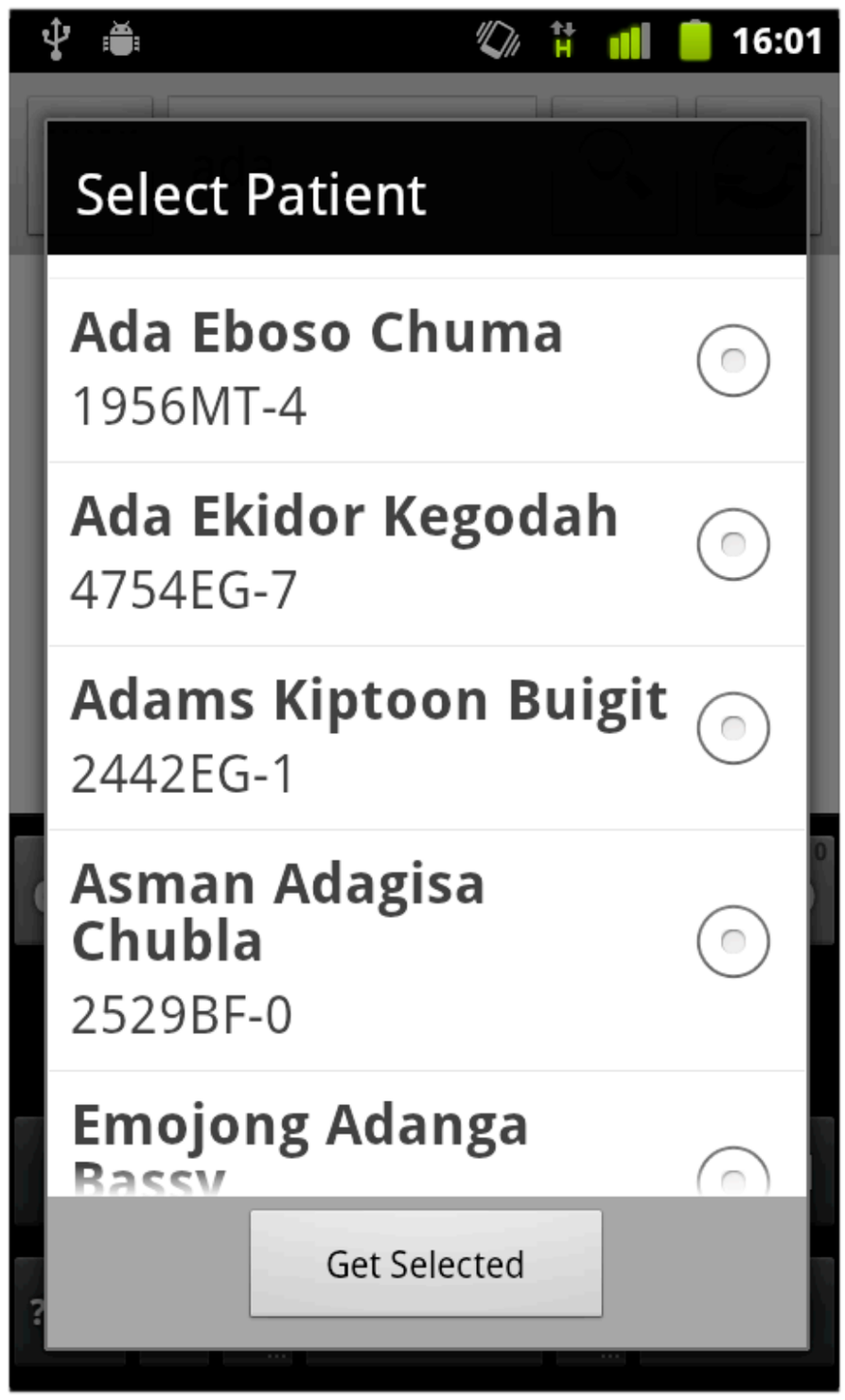


if a clinician wants to order a lab, we mirror the paper lab order sheet. and after they choose the tests, we generate the same paper form they are familiar with and print it wirelessly to the nearest printer.

this is done because ampath's lab system and workflow don't really support sending the lab order data from the phone.

Local search and remote search



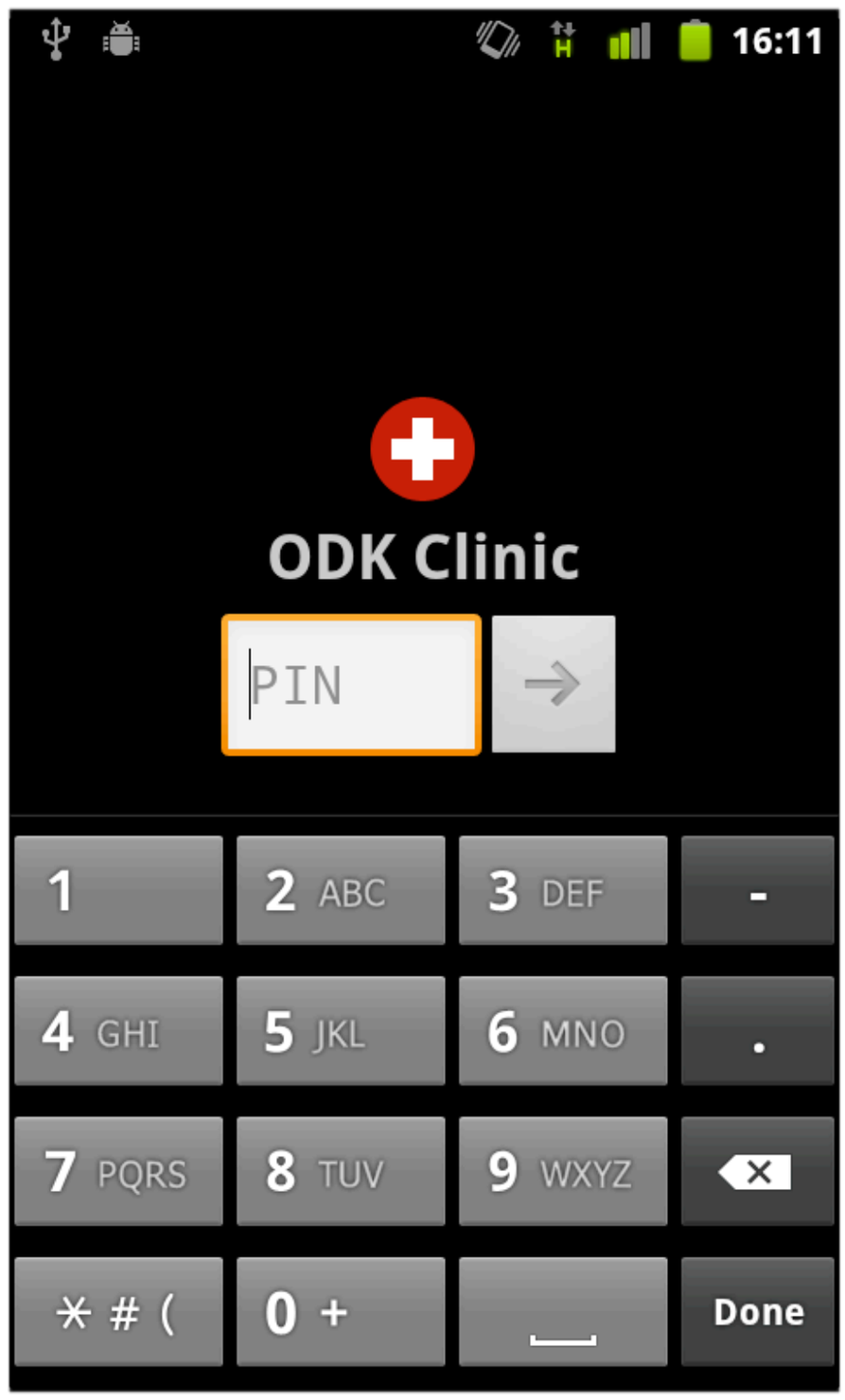


when clinicians are done, they go on to the next patient.

the ui supports live searches against patient name and id.

if the patient isn't on the phone, they can do a search against all 130k patients on the server and download the record.

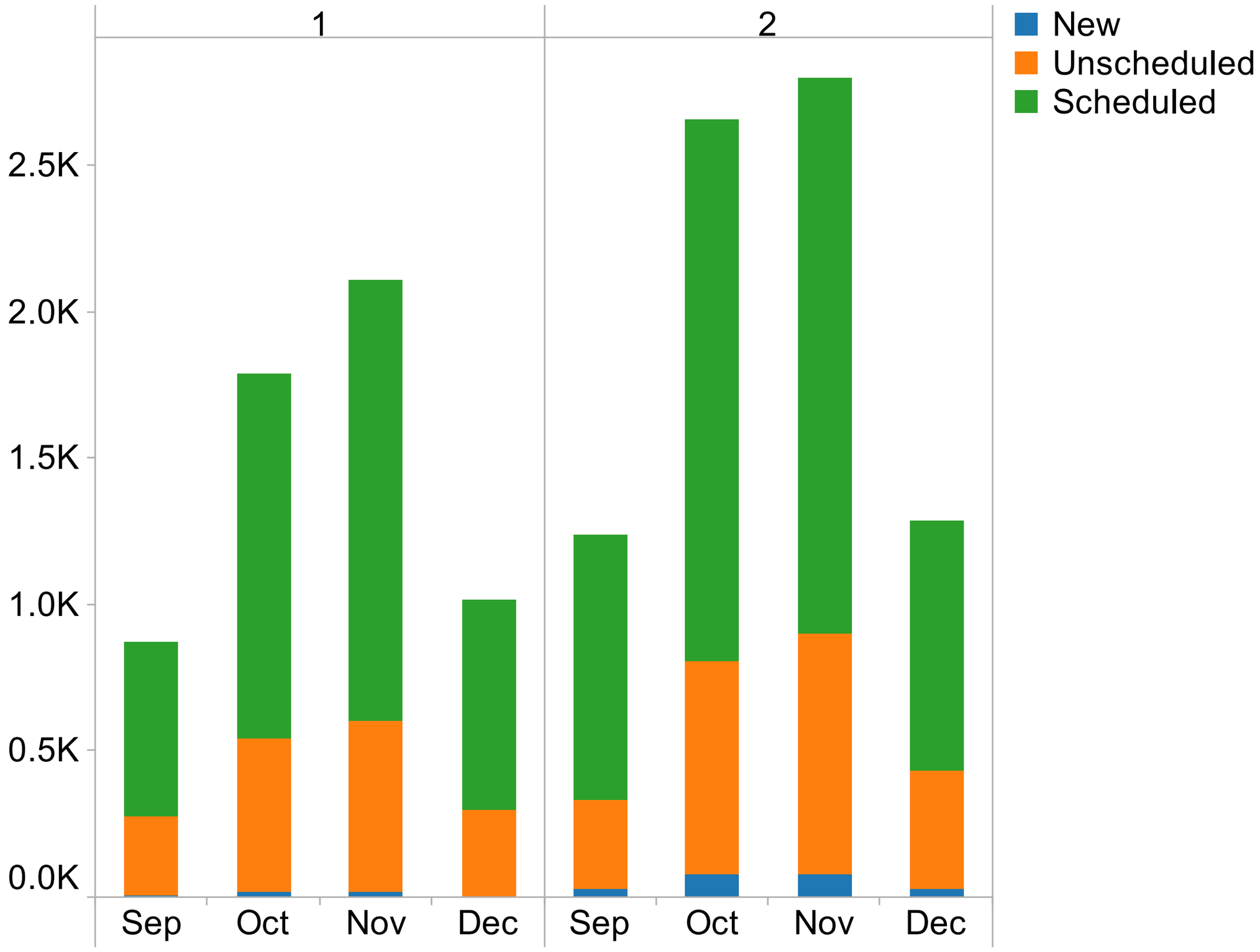
Barcode scanning and security



and finally, clinicians can also scan barcodes if the patient has a barcoded patient card, and the application secured with pins and encrypted in transmission.

So that's the app.

Three month deployment at two clinics



We deployed the system at two adult HIV clinics that see lots of patients.

These are urban clinics, located in Eldoret (the main location) and there are basically two clinics physically in the same building. These numbers are not from the phone, but from the statistics that AMPATH keeps.

The clinics are on the X-axis, along with the time period. The Y-axis is the number of patients seen. And the colors are the type of patient.

The study period starts in mid-September and ends in mid-December which is why those bars are low.

You can see that there are few new patients (blue), but large numbers of unscheduled patients (orange, about 30%). Even for the patients that are scheduled (the green), those are the ones who showed up.

Depending on what day it is, 50%-80% don't show up. So you end up printing lots of summaries that you don't need for the scheduled patients. And you end up printing lots of summaries that you do need when the unscheduled patient shows up.

Across the two clinics, we looked at 12 providers who were active users of the system. There were about 13k patient encounters.

So what did we learn that can be used to strengthen the CDSS?

Initial findings from deployment

- Availability of decision support at point-of-care is much better than with paper system.
- Clinicians can now quickly correct wrong drugs and labs seen in patient record.
- Supervisors have detailed and objective view of decision support process.
- **Come to my defense on March 8th to find out more!**

there are some other benefits that we've seen.

availability at the point of care is basically perfect now -- when a clinician needs patient data, they just look it up. it works well even when the medical record system is down.

clinicians can now correct mistakes (wrong drugs, wrong labs) they see in the patient record and that data goes directly to the medical record system.

supervisors now get a detailed and real time view of what is going on. they know when clinicians see patients, how long they see them, if and when they respond to reminders. and this is great information that is needed to make reminders more useful.

so now if supervisors see a deviation in care or something going wrong, they know who they have to talk to. and it's all transparent and objective -- the data speaks for itself.

“I can't see a patient without this phone”

i was just in eldoret a few months ago, and one of the things the clinicians said over and over again was that they can’t see a patient without the phone.

i’ve been working with clinicians for a while now, and i hate to stereotype, but they definitely let you know if there is a problem. so far, there haven’t been any complaints and that’s been great.

it’s fast and easy for them to use and they’ve gained a lot of functionality. they can look up patient data whenever they want, they know when they correct mistakes it goes directly to the medical record system, and the application helps them conform to doing the right thing.

ODK Clinic evolves and magnifies an existing system

for me, the bottom line is odk clinic, is really an evolution of a system that ampath created. we've been able to make that system better with odk clinic. and that's what my goals are. take a process that works, make it more efficient, and try to magnify the impact.

ampath is convinced that this is improving adult hiv care so we are now moving on to maternal and peds care. we already have paper summaries and i'm hoping we will have similar impact there.

Some database-y problems

- How do you help hospitals evolve a system that starts out with paper, moves to Excel, then Access, eventually to MySQL? Or can you go the other way?
- What is the best way to synchronize patient data in databases across disconnected environments? Possible to do this on mobile (maybe with CouchDB)?
- What about tools that enable individuals to better clean, query and understand their data? Think Google Refine or Tableau, but even easier.

the first principle was to support a variety of summary types. for example, the system should be able to create a summary for a pharmacist with prescribed medications and reminders about drug interactions.

network connections, even internal to ampath are unreliable. we wanted the mobile client to work offline by default and download/upload intelligently. this also helps with making everything as fast as possible for clinicians.

in our work on odk collect, we've learned that a lot of our users have calloused fingers and uncorrected vision. this makes it hard to use a touchscreen -- they need soft fleshly fingers to work. so, we use large, high contrast, and consistent widgets that users can hit. these are pretty standard ui tricks, but it's even more important when you want to drive down training costs.

we mirror the paper summary as much as possible. for example, because clinicians are trained on reading lab values in columns, we do not graph lab values. we also only display data that is important to decision-making. as users grow familiar with the phone-based system, we expect this to change.

odk clinic is just for the summary sheet and nothing else and so that's all the functionality we provide. clinicians still have to use the encounter form, even though it could be implemented as a form on the phone with odk collect.

why? well, encounter forms are at the heart of every patient encounter at ampath. changing the process is logistically impractical. instead, ampath sees replacing paper summaries with odk clinic as the first step in understanding how to replace the paper encounter forms with tools like odk collect.

A group at the University of Washington exploring how technology can improve the lives of underserved populations.

http://cs.washington.edu/homes/yanokwa (@yanokwa)

http://change.washington.edu (@uwchange)

http://opendatakit.org (@opendatakit)

if you are interested in this kind of work, i founded a group at uw called change that does projects of this kind. check us out http://change.washington.edu or on twitter.

we do a lot of mobile health work, everything from portable ultrasounds, spirometers that run on phones, management tools for community health workers, algorithms that can detect fake data, low cost sensing platforms for dumb and smartphones, vision apps for reading assay cards, etc. most of our work is actually out in the field and working.

my website also has links to the papers that i referred to in this talk. so with that, are there any questions?