ODK Clinic

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

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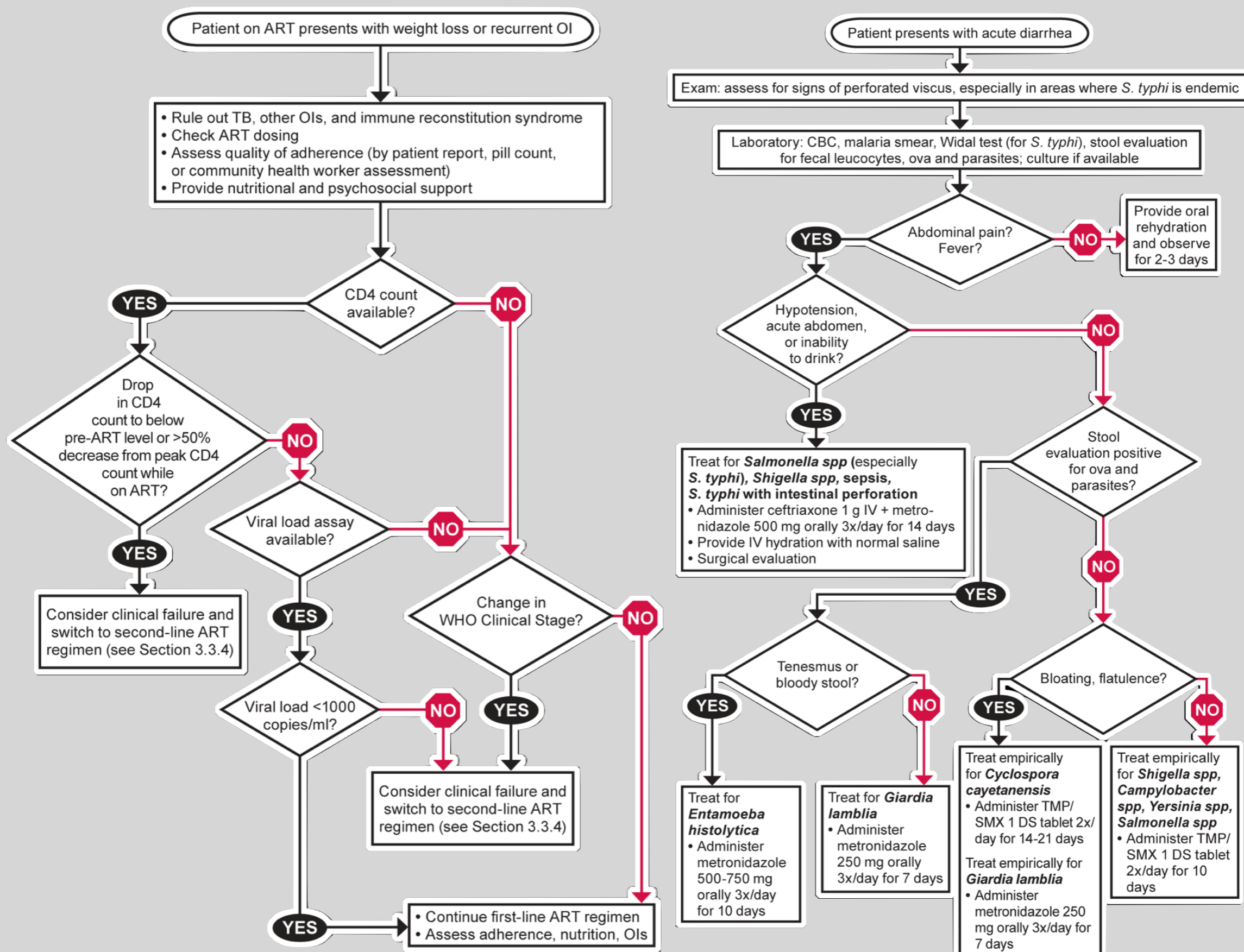Tapan Parikh, Gaetano Borriello, Martin Were

My name is Yaw Anokwa. I just finished my Ph.D. in Computer Science from the University of Washington and I'm one of the creators of Open Data Kit or ODK.

This talk is about ODK Clinic, which is a new ODK tool designed to improve clinical decision support in low-income regions.

This is work that is done with Win Ribeka, Tapan Parikh, Gaetano Borriello and Martin Were. Win and Martin are from Regenstrief Institute, Tap is at the iSchool at Berkeley, and Gaetano is from UW-CSE.

This work has progressed quite a bit since the paper was written, so I'll try to focus this talk on the findings in the paper that I have more evidence for.

HIV/AIDS is a complex disease that weakens immune systems

Left flowchart:

Patient on ART presents with weight loss or recurrent OI

- Rule out TB, other OIs, and immune reconstitution syndrome
- Check ART dosing
- Assess quality of adherence (by patient report, pill count, or community health worker assessment)
- Provide nutritional and psychosocial support

CD4 count available? — YES / NO

YES → Drop in CD4 count to below pre-ART level or >50% decrease from peak CD4 count while on ART? — YES / NO

YES → Consider clinical failure and switch to second-line ART regimen (see Section 3.3.4)

NO → Viral load assay available? — YES / NO

YES → Viral load <1000 copies/ml? — NO / YES

Change in WHO Clinical Stage? — NO / YES

YES → Consider clinical failure and switch to second-line ART regimen (see Section 3.3.4)

YES →
- Continue first-line ART regimen
- Assess adherence, nutrition, OIs

Right flowchart:

Patient presents with acute diarrhea

Exam: assess for signs of perforated viscus, especially in areas where *S. typhi* is endemic

Laboratory: CBC, malaria smear, Widal test (for *S. typhi*), stool evaluation for fecal leucocytes, ova and parasites; culture if available

Abdominal pain? Fever? — YES / NO

NO → Provide oral rehydration and observe for 2-3 days

YES → Hypotension, acute abdomen, or inability to drink? — YES / NO

YES → Treat for *Salmonella spp* (especially *S. typhi*), *Shigella spp*, sepsis, *S. typhi* with intestinal perforation
- Administer ceftriaxone 1 g IV + metronidazole 500 mg orally 3x/day for 14 days
- Provide IV hydration with normal saline
- Surgical evaluation

NO → Stool evaluation positive for ova and parasites? — YES / NO

YES → Tenesmus or bloody stool? — YES / NO

YES → Treat for *Entamoeba histolytica*
- Administer metronidazole 500-750 mg orally 3x/day for 10 days

NO → Treat for *Giardia lamblia*
- Administer metronidazole 250 mg orally 3x/day for 7 days

NO → Bloating, flatulence? — YES / NO

YES → Treat empirically for *Cyclospora cayetanensis*
- Administer TMP/SMX 1 DS tablet 2x/day for 14-21 days

Treat empirically for *Giardia lamblia*
- Administer metronidazole 250 mg orally 3x/day for 7 days

NO → Treat empirically for *Shigella spp*, *Campylobacter spp*, *Yersinia spp*, *Salmonella spp*
- Administer TMP/SMX 1 DS tablet 2x/day for 10 days

HIV/AIDS is a chronic disease and it's been absolutely devastating to the poor in Africa. The virus weakens the immune system, and so patients gets sick from a wide array of diseases.

Managing HIV is really about treating all those diseases, often at the same time. The treatment protocols can be really complex. Let me give you an example.
*
This is just the treatment protocol for a patient suffering from weight loss and diarrhea. You don't have to read this, I just want to show that it is complicated.

Add a serious illness like tuberculosis on top of this and the treatments get even more complicated.

Complexity is a problem because

HIV care is often delivered by busy doctors with little training

This situation can result in sub-standard care for patients

In developing countries, HIV care is primarily delivered by doctors with relatively little training. And most of these doctors work in hospitals that are under-resourced and busy. Kind of like this.

Just for some perspective on how under-resourced, the US has one doctor per 400, Kenya has one doctor per 7,000. And that's across the entire country. The ratio is likely worse in rural areas.
*
And as you can imagine, the combination of complex treatments, and lightly trained doctors and busy clinics can result in sub-standard care of patients.
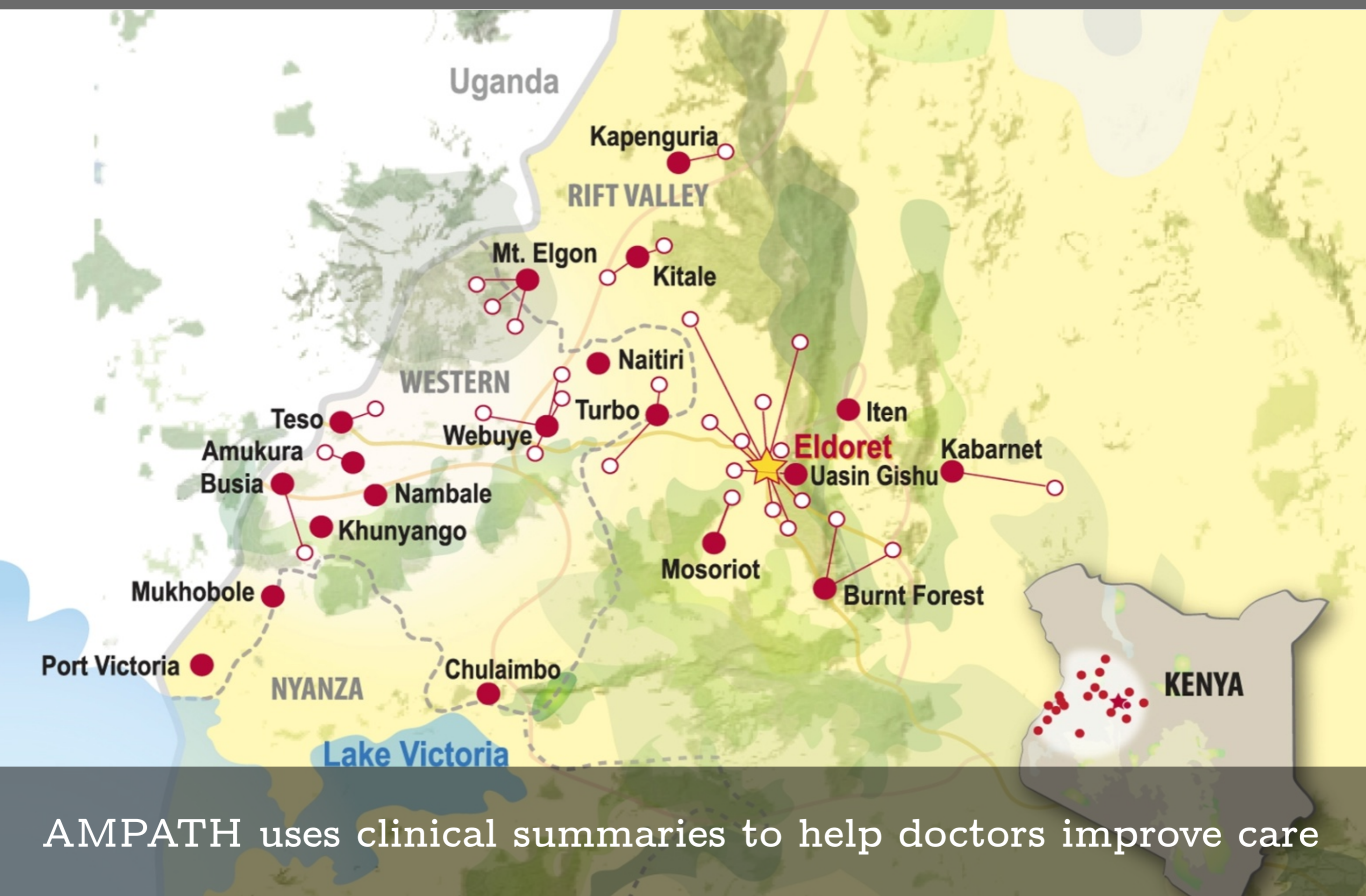
AMPATH uses clinical summaries to help doctors improve care

This is a challenged faced by AMPATH, one of the largest HIV treatment programs in Sub-Saharan Africa.

They provide care to more than 130,000 active HIV patients through 52 clinics, which you see here as the red dots.

AMPATH is in the Western Province of Kenya, and they have a huge catchment area with 2 million people.
*
Over the last few years, AMPATH has used printed clinical summaries to provide some assistance, some decision support, for doctors who are seeing patients.

What's a clinical summary?

Demographics →

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)*

Problems →

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

Recent ARVs & OI Meds
1. TRIMETHOPRIM AND SULFAMETHOXAZOLE

← Medications

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*						

Lab tests →

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

Reminders : (Write number next to each reminder)
1-Ordered Today, 2-Not Applicable, 3-Previously Ordered, 4-Pt Allergic, 5-Pt Refused, 6-I Disagree with Reminder, 7-Other(Explain)

1. Please order HIV ELISA. Pt > 18 mo old with no valid ELISA result. (___)
2. Consider starting ARV Meds. Pt > 5 yrs with positive DNA PCR AND CD4 Count < 500 (___)

Reminders →

Last seen 31/03/2010 at MTRH Module 1 by The Super User
Encounter entered by The Super User on 01/03/2010   **014021634-2**
Next scheduled visit: 03/01/2007

Clinical summaries are a one page sheet that is generated from AMPATH's electronic medical record system, or AMRS. It gives a nice overview of all the relevant patient data. It looks like this.
*

It has the patient's demographics,
*

the problems they are having,
*

recent medications, and
*

recent lab tests.

So it's a one page overview of the patient. Nurses print this summary when the patient arrives and give it to the doctor.

One of the most useful things about the summary are the reminders.
*

These are patient specific reminders to the doctor about how the patient is deviating from these complex care protocols.

If the medical record system, AMRS, sees that the patient is late for a test according to standard care guidelines, it prints a little reminder at the bottom for the doctor to follow.
*

And there is very convincing evidence from the developed world, and at AMPATH that these summaries with reminders improve the quality of care.

That's great, but unfortunately, there are problems with the whole printed summary process. Let me go over those.

- ## Summaries are not always available

  A patient visit without the assistance of a summary potentially had sub-standard care.

- ## Summary usage is difficult to measure

  Summary usage is an important metric for supervisors who monitor quality of care.

- ## Corrections are not added quickly to record

  Slow correction of medications and labs affect patient care and usage of summaries by doctors.

So what's the problems with summaries and why do they matter?
*
First, the summaries are not always available. That is when a patient shows up, their summary may not be printed by nurses and placed in their patient folders.
*
This is a problem because a patient visit without the help of summaries and reminders potentially had sub-standard care. We don't want to take that chance.
*
Second, the summary usage is hard to measure. When the doctor sees the summary, they are supposed to put a big slash mark through it. They don't always do it.
*
Summary usage is an important metric for supervisors who monitor the quality of care. Not knowing if doctors are using the summary is a problem.
*
Finally, corrections are not added quickly to the patient record.

The data in the medical record system that is used to generate the summaries, is not always correct. Doctors correct the summary, but these corrections take a long time before they are applied to the patient's electronic record.

I'll explain why this is in a second, but take my word for it for now.
*
Slow corrections of medications and labs affect patient care and usage of summaries by doctors.
*
Let's start with the first problem of summary availability and dig a little deeper.

Analyzed data on availability rates for summaries for patient return visits in 18 AMPATH clinics. This data was collected by AMPATH from September 2010 to January 2011.

Across 51k visits, 20% (10k patients) did not have summaries.

Over a five month period, I looked over the data AMPATH collected at 18 of their clinics as part of routine care.
*
I analyzed the data from 51k patients, and across those visits, 20% of patients did not get summaries. You can find the details of that in the paper.
*
The way I got this data is that the nurses maintain a daily count of all patients that are seen. Another group of staffers count all the summaries that are printed from the sites each day, and see how many summaries they have. That discrepancy is the 20%.

Beyond that data, I spent a fair bit of time at AMPATH clinics. I watched the workflow at a few clinics, I talked to stakeholders, and the takeaway is that the system for printing and delivering summaries is fragile.

There are lots of reasons for this that I document in the paper, but let me give you an example.
*
It's often the case that the nurses in charge of printing are overwhelmed with taking care of patients sand are too busy to print the summaries.

Even if they aren't busy, when there are issues with printing, they don't report those issues. It can take days or weeks before a supervisor finds the problem and starts addressing it.

During that period, patients are being seen without summaries and that's problem.

Let's move on to the second issue with summaries.

Summaries usage is difficult to measure

Doctors ignore procedures and manual monitoring is inefficient

Summary usage is difficult to measure. Again, this is important because summary usage is a critical metric for supervisors who monitor quality of care.

Doctors are supposed to put a big mark on the summary sheet, like this.
*
And then supervisors go to each site once or twice a week and basically count the marks on the summaries.

But doctors don't always mark the summaries. Why?

Sometimes they forget, sometimes they ignore this procedure.
*
Regardless, the current paper system doesn't make it easy to monitor usage.

You literally have to go visit all the sites in western Kenya and count marks on sheets of paper. It's important for AMPATH to know if the summaries are being viewed and current practice is pretty inefficient.

So that's the second problem. Let's move on to the final problem with summaries.

1. Doctor completes paper form documenting patient encounter.
2. Encounter form is entered into the electronic record by clerk and returned to folder.
3. Electronic record generates printed summary for patient return visit.
4. Discrepancy between forms and summary is seen by doctor during visit and corrected.
5. Summary corrections are collected and sent for data entry and quality checks.

The third problem is that corrections are not added quickly to the patient's electronic record, and that slowdown in correction of medications and labs affect patient care and usage of summaries by doctors. Let me explain why.
*
During each visit, a doctor fills out an encounter form. It is the form that documents everything that happened during that visit.
*
That form is eventually then typed (often with mistakes introduced) into the medical record system. The entry is done by a data entry clerk who has no medical training. The forms are then returned to the patient folder.
*
It is the electronic data, which is supposed to be ground truth, that gets synthesized into the printed summary when the patient returns.
*
So during a return visit, when a doctor sees a discrepancy between the hand written encounter forms and the printed summary, they are supposed to note and correct that discrepancy on summary.
*
Then the corrections on the summary are again entered by a data entry clerk into the record. Where again, they may make more mistakes, and the cycle continues.
*
Let me give you an example.

This picture of a missing lab test on the summary. So the doctor has seen the lab result of 1602 on the encounter form in the patient's folder, but somehow the data did not get entered in the patient's electronic record, so it's missing in the summary.

These corrections are especially important for medications.
*
Why is this? Lots of reasons, but the biggest problem is that it turns out the data entry team is always busy with entering all the other paper forms in the hospital and so corrections take a long time to enter and get approved by the data quality team.

After doctors correct the same mistake multiple times, they end up getting irritated and stop correcting.

That's terrible because you aren't getting corrections of bad medication or lab data by medically trained professionals who are physically there with the patient.

That's a big challenge.

So to summarize the problems I wanted to solve,

Problems

- Summaries are not always available.

- Summary usage is difficult to measure.

- Corrections are not added quickly to record.

Why Mobile?

- Summaries are not just for doctors, but for community health workers, pharmacists, etc.

- Logistics of installing and maintaining computers are non-trivial.

- Phones have been successful at AMPATH with over 650k encounters using ODK Collect.
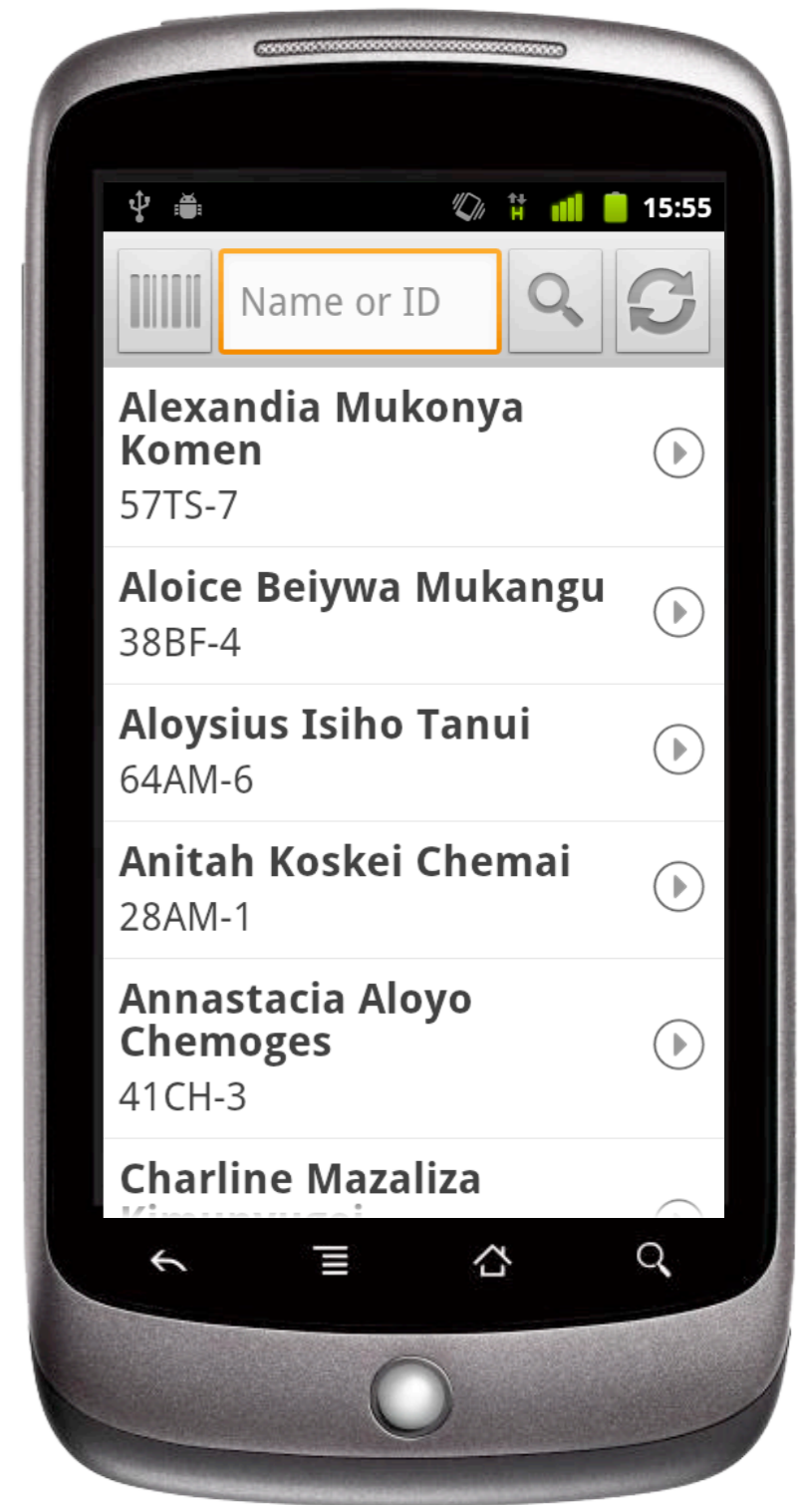
Summaries are not always available. Usage is difficult to measure. Corrections are not being added quickly to the record. I detail others in the paper, but let's focus on these.

A lot of these are limitations of a paper–based system, and AMPATH has been trying lots of techniques to improve this system. As part of that work, they wanted to try to see if an electronic system would work better.
*
I thought it would. In particular, I believed that building a mobile application would be a good first step towards solving these problems.
*
So why mobile and not say a desktop app?
*
First, summaries are not just for HIV doctors. AMPATH is moving to a model of care where patients don't come to the hospital. They go to their dispensary nearest their house where a lightly trained nurse or pharmacist will check vitals and if everything is proceeding OK, they don't have to travel to the hospital. Mobile summaries are perfect for those situations.
*
Second, the logics of installing desktop computers in African hospitals is non–trivial. Just ensuring they have reliable power is a full time job. There just isn't a lot of technical capacity to manage all those computers. Mobile devices just work better.
*
Third, mobile devices are just a really nice fit at AMPATH. They have had great success scaling phones. For example, they've used ODK Collect, another one of our tools, in over 650k community health care visits.

So we figured, why not try it again with ODK Clinic. Let me show you what I built...

ODK Clinic caches 14 days of summaries for offline use
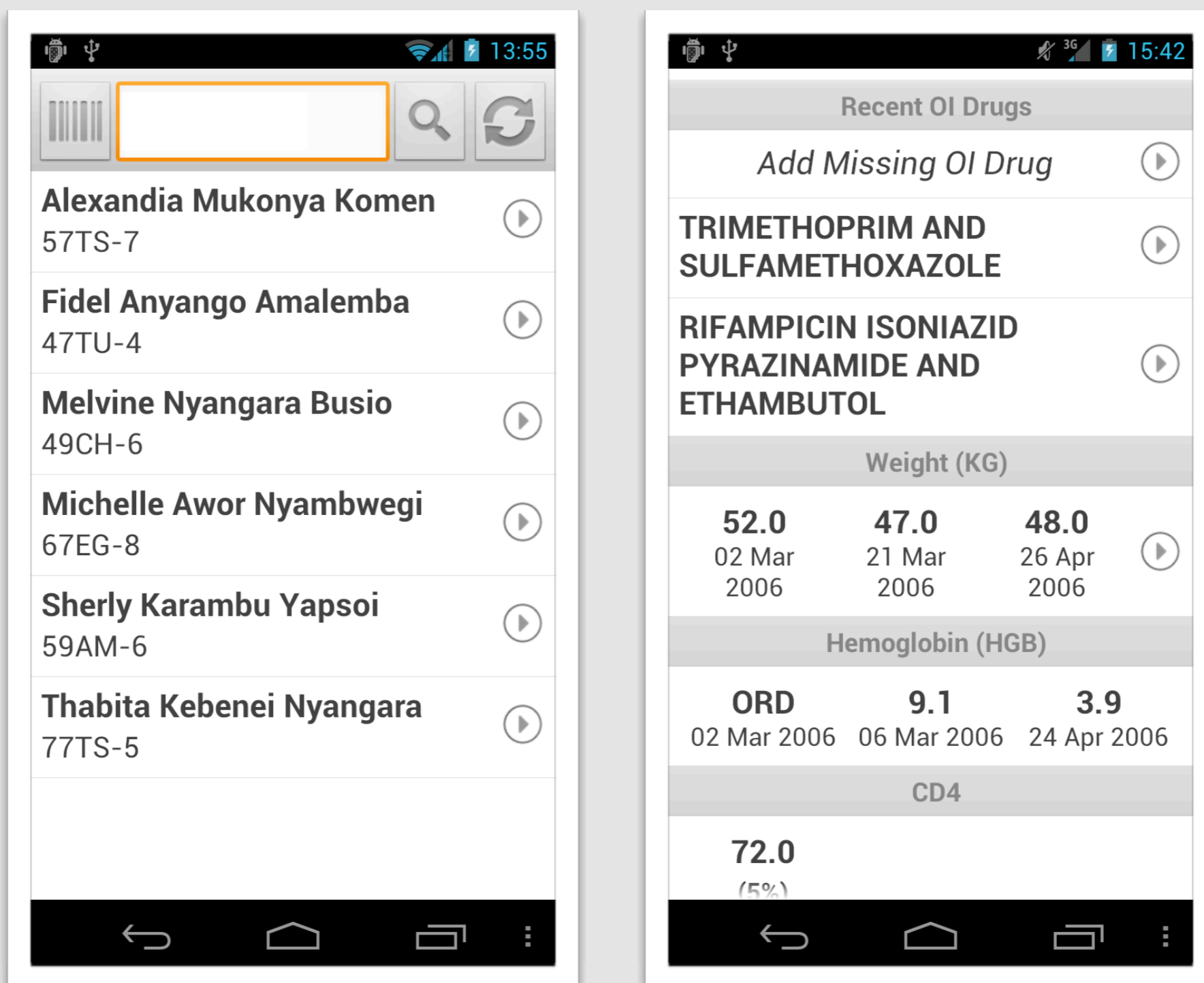
Summaries are functionally and visually similar to paper

Clinic is an Android app that replaces the summary and the main screen looks like this.

Each doctor gets a phone and in the morning, they download a big batch of patient summaries from the medical record system to the phone.

ODK Clinic downloads scheduled patients in a two week range. These are the summaries of patients that are likely to visit a week before today and a week from now. All that data is stored on the phone for offline use.
*
The app is structured that way because medical record system is pretty unreliable.

As one staffer said, "It's usually not down for more than 30 minutes, but it goes down every hour or so."
*
When a doctor taps on a patient, the summary of the patient is loaded.
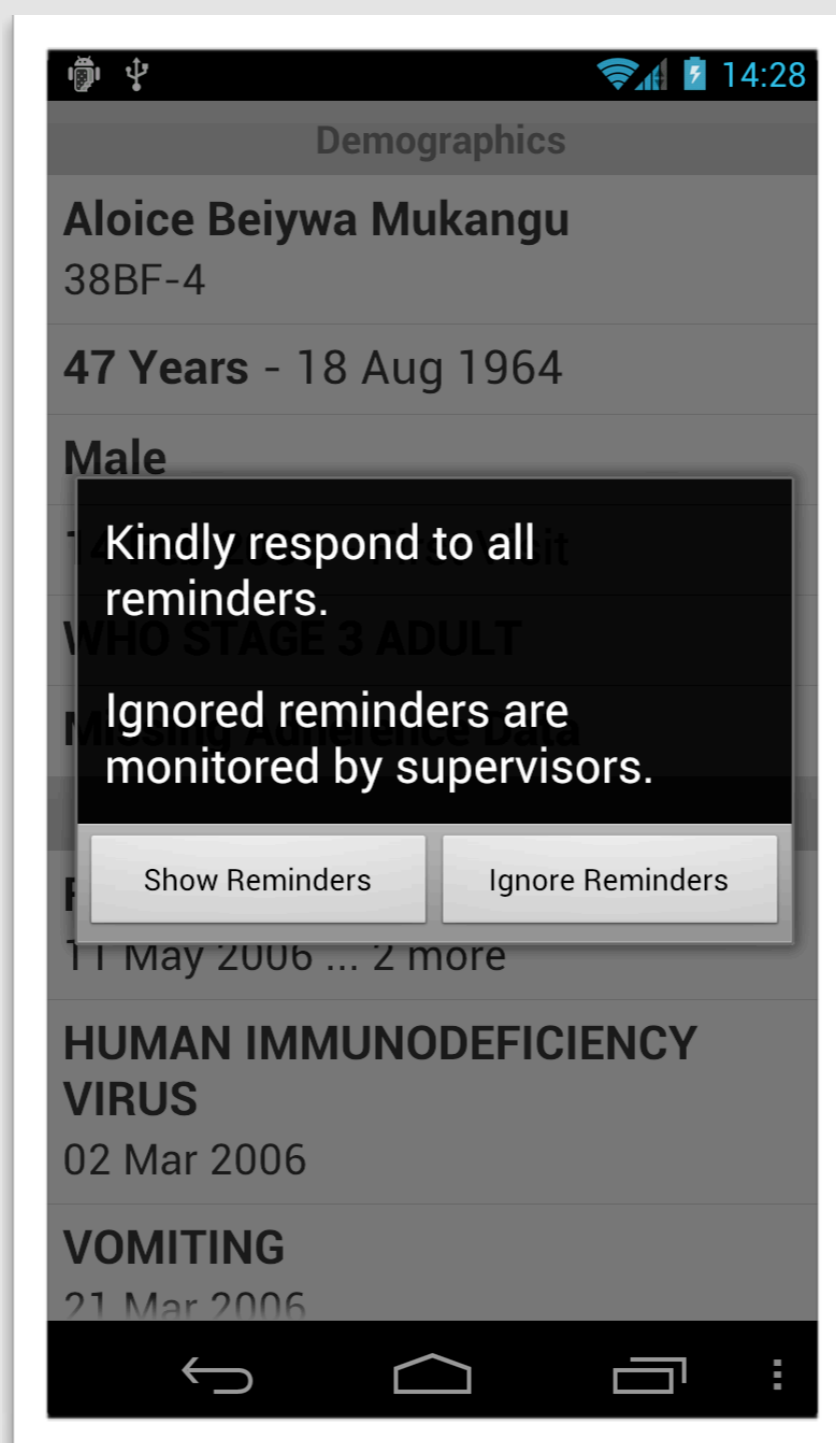*
The summary on the phone is functionally and visually similar to the paper summary. That is whatever you do on the summary sheet on paper, you can do on the phone summary.
*
As far as things like visualization. You might think that the phone could enable more visualization, but it turns out those visualizations require more a lot more training and that can get expensive.

So that's an overview of how I address availability.

I have prompts through out ODK Clinic that are designed around the standard operating procedures that AMPATH has.
*
For example, if a doctor doesn't respond to reminders in the summary and tries to exit, they are reminded to respond to reminders.

The goal here is to help doctors follow standard operating procedures.
*
And as a bonus, the details of how ODK Clinic is used is logged daily and is sent back to the medical record system where it can be analyzed.

This solves one of the problems I defined earlier with monitoring usage. Now supervisors do not have to go to every site and pick up old summary sheets and count if the doctor has put a slash on it.
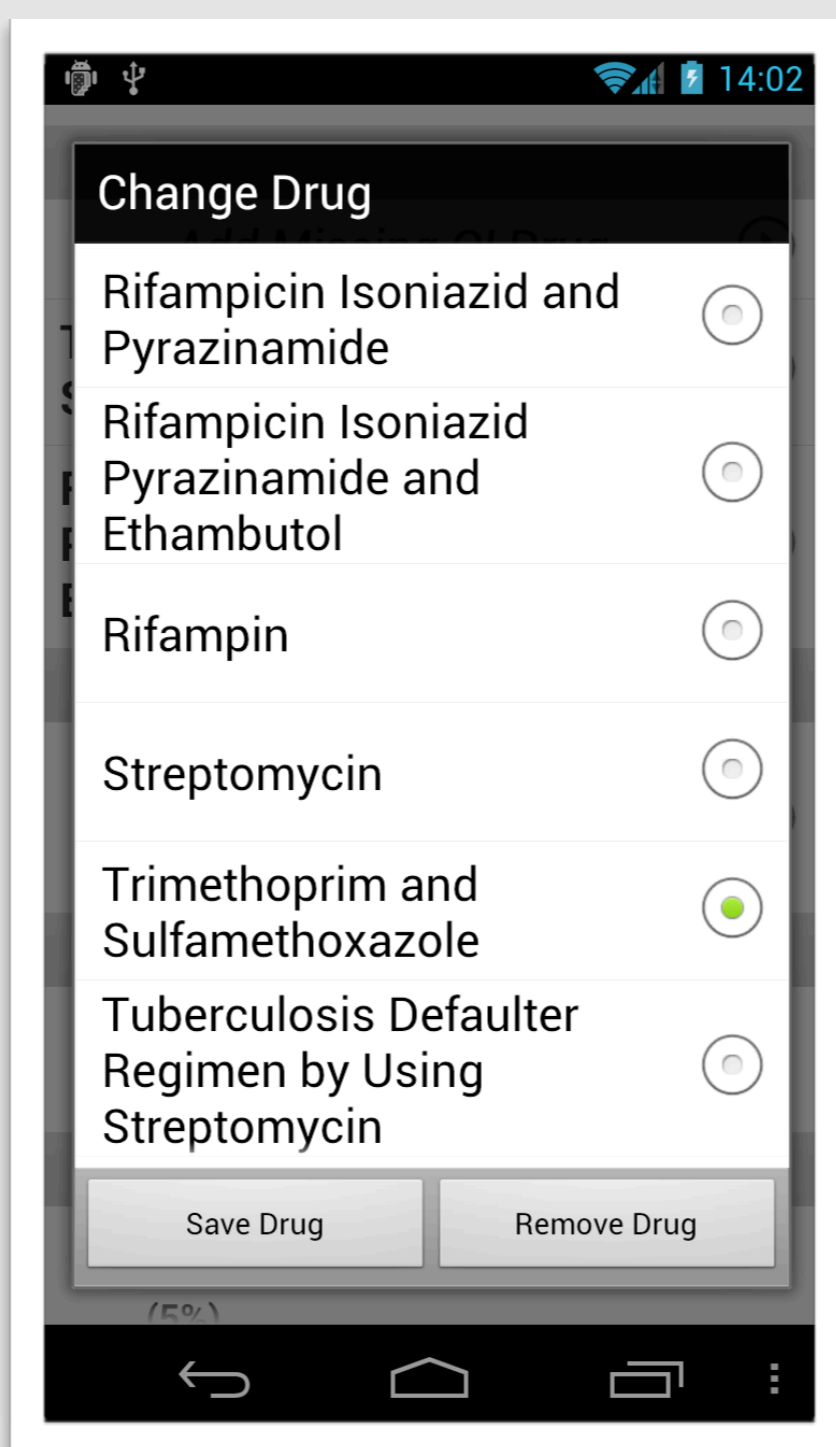
Finally, since data from AMRS is not always correct, I added the ability to correct mistakes. These could be previously ordered labs or in this image, medication errors.

When a doctor sees a mistake in the medications of a summary, they can double-check with the historical encounter forms in the patient's folder, and also ask the patient what medications they are taking. If there is a discrepancy, they correct it right there in the summary.

Because it's on the phone, it's not handwritten free-text, it's strongly coded.
*
This is a big deal because it means that you don't have to manually collect all the corrections from all sites, transport them to a central location for data entry and try to interpret the doctor's handwriting.
*
The changes are just automatically sent to the medical record system at the end of the day. Which solves the problem of corrections...

So this is all nice and all, but does it actually work in the real world?

It seems to.

It's been some time since the paper was accepted, and during that time, ODK Clinic has been running at two adult HIV clinics at AMPATH.

The system has been in use for about seven months, and there are now about 20k patient encounters.

We have lots of data about how the system is being used, but I wanted to share the evidence we have that strengthen the findings I detailed in the paper. I'll start with some anecdotes...

"I do not depend on other staff to print for me [the] summary ... [or] to put the summaries in charts [patient folder]. I can assess AMRS with the phone while in the room thus enabling me to make corrections."

*
"I do not depend on other staff to print for me the summary ... or to put the summaries in patient folders. I can assess AMRS with the phone while in the room thus enabling me to make corrections."

Across all doctors, you get the sense that they really like the independence this enables.

And this strengthens one of the findings from the paper, that doctors want to do the retrieval and correction themselves. They want to own that process.

"When we were rolling down this thing, someone thought I was doing Facebook. So when I realized that, I started educating our patients. If a patient comes in, I tell them, look, this gadget is your file [patient folder]. I'm going to use it to have a look at your case. And now they understand. So the interaction is good."

We were concerned about how patients would react. It seems that patient interaction is better if you explain phone usage. One doctor said...
*
"When we were rolling down this thing, someone thought I was doing Facebook. So when I realized that, I started educating our patients. If a patient comes in, I tell them, look, this gadget is your patient folder. I'm going to use it to have a look at your case. And now they understand. So the interaction is good."

I think this quote speaks volumes. The obvious thing here is that a patient, when you educate them are OK with the technology. I dug a little deeper and you get this sense from the doctors, that patients actually appreciate the technology.

That is, as a patient if you see a doctor using technology, you seem to think that doctor is more advanced, and maybe better in some way.

Whether that's true or not remains to be seen, but the notion that patient interaction isn't hurt strengthens another finding we had in the paper.

"If the problem was happening every day, the solution is not to go back to the paper work. The solution is to look where the problem is and we sort it out."

"It's a part of me now. I really can't see a patient without this phone. It's like something is amiss."

But overall, doctors they seem to like ODK Clinic. There is a can-do and aspirational side of using the technology, especially with the younger doctors.
*
"If the problem was happening every day, the solution is not to go back to the paper work. The solution is to look where the problem is and we sort it out."

That is not to say that the system is perfect, but I think there is recognition that ODK Clinic is there to help improve their care of patients.
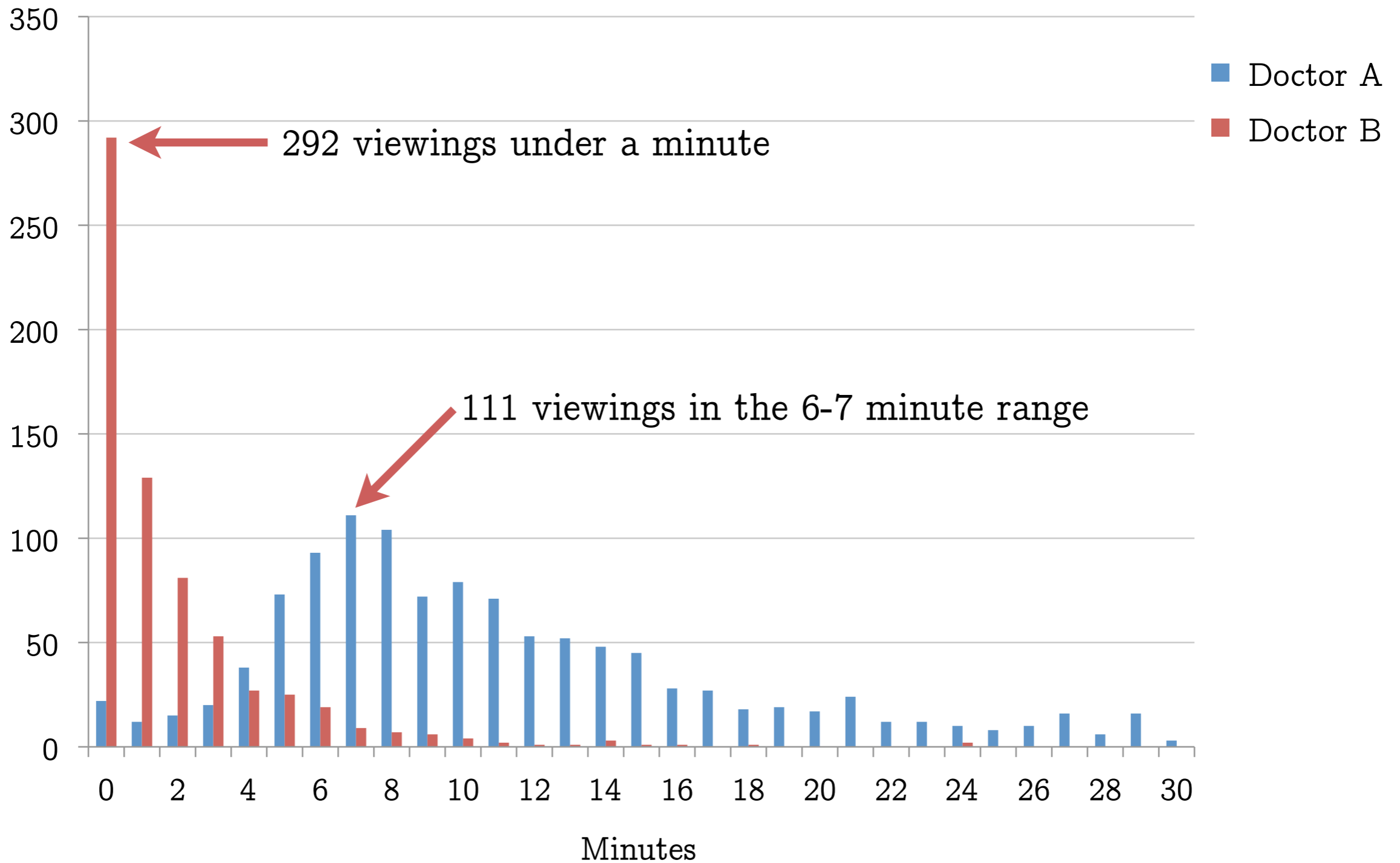
Two of doctors said something like this.
*
"It's a part of me now. I really can't see a patient without this phone. It's like something is amiss."

I think the really big contribution in this work is for the supervisors. They gain greater visibility into the system. Let me give you an example.

Frequency of Summary Viewing Lengths

It turns out summary viewing patterns vary widely by doctors. That is, for each patient visit, how long do they have the summary open.

Let's start with Doctor A.
*
Here on the X-axis is the number of minutes that a summary was open for that patient. The Y-axis is the frequency or count.
*
So for example, of all the summary viewings that Doctor A had for the study period, 111 of them were in the 6-7 minute range. This is what I expected, but turns out some doctors deviate from this pattern.

Here for example is Doctor B. Notice there are 292 viewings under a minute.
*
This data does not mean that Provider B is not really seeing patients. She might just open and close the summary at the end of the patient visit to make sure nothing was missed, instead of keeping it opening during the whole time.

The fact that I can now document this is a contribution that helps AMPATH monitor usage to find variations like these, and then follow up.

That said, there is a lot more work to do in this space.

- Even more patients to the phone

- Increased flexibility in summary definition

- Tablet form filling to replace encounter forms

- Tools to visualize breakdowns in workflow

- Does mobile increase quality of care?

*
Even more patients to the phone.

One big limitation in this work is just how poorly I handle patients who fall outside the two week end. These patients are not expected to visit and so doctors have to do a search against the medical record system to download the summary. If AMRS is down, those summaries aren't available.
*
Increased flexibility in summary definition.

There is a lot of business logic that sits on the phone client. I think all that could be encoded in a more flexible summary definition.

This is important because as you scale, you can't always update the phones. You want to put as much logic into the server as possible.
*
Tablet form filling to replace encounter forms.

Doctors adapted quickly to touch. Could we leverage this to build richer form interaction, say on a tablet?

I stayed away from the encounter form because it's just too big and complex to do well on a phone. I've got some ideas of how I can do it better on a tablet and doctors are really excited about those possibilities.
*
Tools to visualize breakdowns in workflow

I think tools that empower local and remote staff to see where there are breakdowns in a workflow would be very useful. We found lots of gaps at AMPATH, and I think tools that empower local staff to find these gaps would be great.
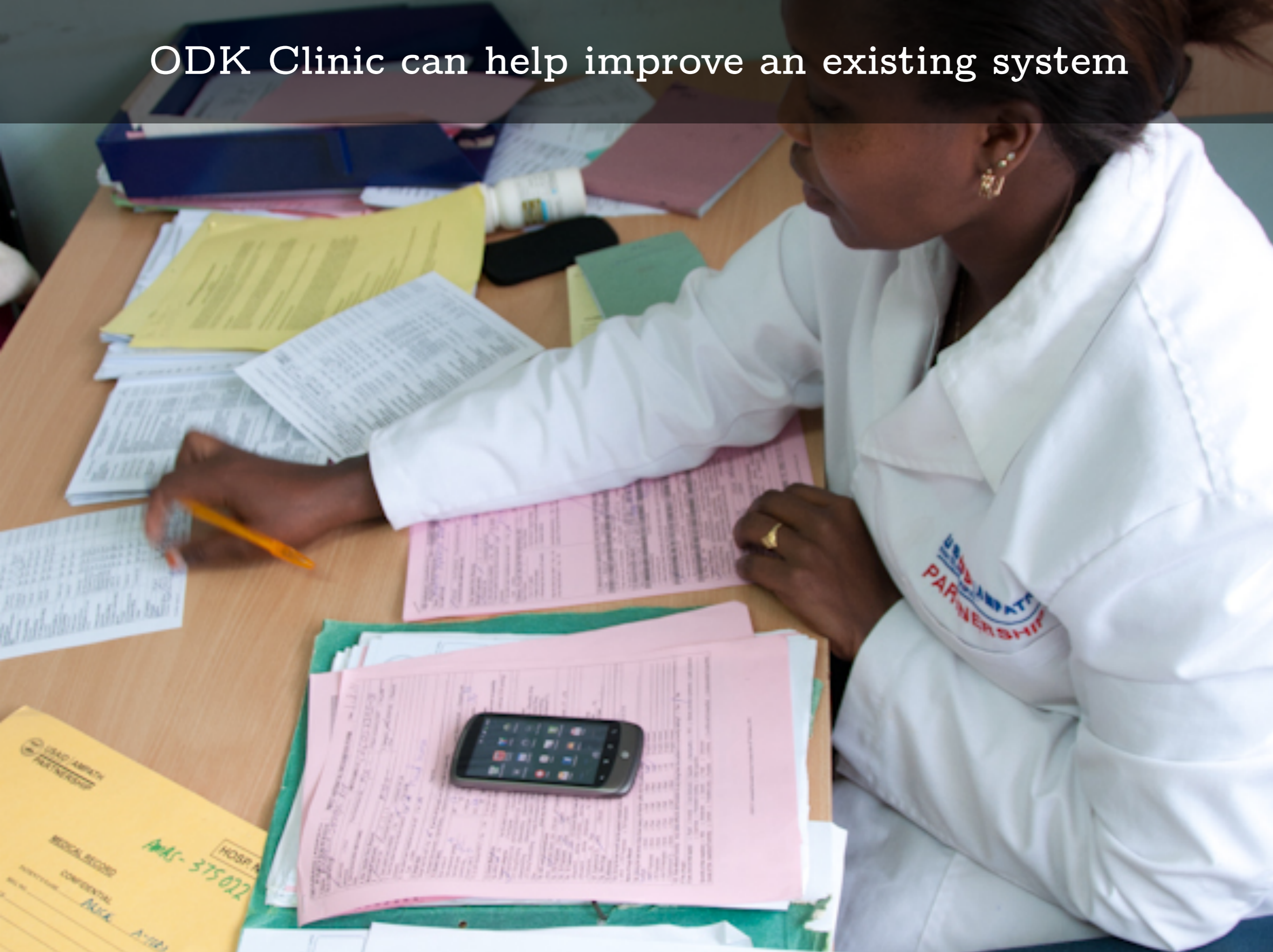*
And then finally, does ODK Clinic actually make a difference in care. That is, with all the support for supervision, and data correction and reminders in the phone, does that actually make a measurable difference in the patient's outcomes.

I've got some data on this, but we need a more controlled and rigorous evaluation to really answer this question.

So to conclude,

The biggest lesson learned here is that technology can really help improve an existing system.

This work has been an evolution of a paper-based system that AMPATH created, and working with them, I've been able to create an electronic version that gives them more capabilities than they had before.

AMPATH is pushing ahead with this work, and I suppose as a researcher, that might be the best I can hope for...

So with that, thanks for listening!

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Are there are any questions I could answer?