Drug distribution? Trust the people

When communities are in charge, malaria treatment, bednet coverage and TB detection rates double, and vitamin A coverage increases - even though distributors are unpaid.
by Robert Walgate

DAR ES SALAAM - From experience with a neglected African disease, cared for only by the African Programme for Onchocerciasis Control (APOC), is coming the means to prevent and treat malaria, and deliver other care such as vitamin A to prevent childhood blindness.

This was what the APOC Joint Action Forum heard recently with increasing excitement in Dar es Salaam, Tanzania, when TDR, the Special Programme for Research and Training in Tropical Diseases, reported on its first two years’ trials of “Integrated Community-Directed Intervention” – CDI – in Uganda, Tanzania, Nigeria and Cameroon.

But delivering DOTS for TB may require more complex solutions, and antiretrovirals for HIV/AIDS were not tested – as they were not available to the communities in the study.

For several years the communities have already been distributing the drug ivermectin to prevent river blindness, using the ten-year old method of “Community-Directed Treatment with Ivermectin” (ComDT), where they select their own distributors from among their own most trusted people.

For the trial, communities were asked to continue with ivermectin and take on the extra burden of distributing home-based management of malaria, insecticide treated bednets, and vitamin A, and to detect TB cases and provide them with DOTS treatment. Distributors were unpaid. Their delivery rates were then measured and compared to control groups where existing delivery methods were used.

Two years into the three-year trial, the results are that in the Community-Directed Intervention areas:

- Malaria home management coverage doubled.
- Bednet coverage doubled to quadrupled.
- Vitamin A coverage was significantly higher.
- TB case detection rate doubled.

However DOTS treatment completion did not increase, at least by this stage in the trial.

There had been concern that the extra burden on the community of delivering new interventions would affect ivermectin coverage, but the results showed that instead of falling, ivermectin distribution actually increased, probably due to the increased contacts distributors were having around the community dealing with other diseases.

Richard Ndyomugenyi, who is Principal Investigator for the study in Uganda, explained to RealHealthNews: “Basically we are looking at five interventions. We are doing the studies in places where we are implementing ComDT with ivermectin for onchocerciasis control. On top of that we are adding on different interventions in different districts to see whether the distributors can cope. Each year we add on an intervention, like home management of malaria, in one district; in another district we add on vitamin A; in another, insecticide treated bednets; in another DOTS for TB. The second year we add on a different intervention in each district.

“Now we have finished two years, and it is quite clear that this process increases coverage for most of the interventions – and even substantially increases coverage for ivermectin, which is quite interesting. Because initially it was thought that if you add on more interventions you would compromise ivermectin coverage, but that’s not the case.

From research to policy-making

The world of river blindness – a neglected tropical disease of fast-flowing river valleys, mostly in West Africa – is relatively closed. What happens when river blindness experts come to one of the big health divisions at the Ministry of Health, like malaria, to be told how to deliver their treatments? How do they receive that?

“Well, perhaps I have an advantage compared with some other researchers – I am also a member of the senior management at the Ministry of Health in Uganda!” said Richard Ndyomugenyi, Principal Investigator for the study in Uganda.

“So all these other programme managers are my colleagues. And we meet almost on a daily basis. So when I sell them an idea in a meeting, with evidence, then they buy it! So this is why this study is so important – these are results – we are not talking from out of the blue! These are the facts, this is what we have found in our study.”

But for the communication, it is also important that it is someone from the ministry telling the story, says Richard Ndyomugenyi. If another researcher came in from another agency, from another country, and told officials that this was wonderful and here are the results, it would not be received so well. “It would be received, but there would be a big hurdle to jump over to convince them. What we have here is health systems research. If the research does not include the implementers, right from the planning, constantly updating them on the findings, and they just come with a report at the end of the day, it is difficult for these guys to implement the results.

“But if we involve them as stakeholders right from the beginning, and they are following up what you are doing, it becomes easy for them to implement, because those results would also be theirs.”

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“The main reason this works seems to be that this process [known as ‘CDI’ for short] empowers the communities to own the process and the programme. So they actively participate in deciding how these interventions should be delivered – so they take an interest in their own programme, and it increases coverage.

“ComDT for onchocerciasis started a long time ago in 1994, pioneered by TDR. We made a study in Uganda and reported in 1996; and based on that study, APOC adopted the ComDT strategy. The alternative method was to distribute ivermectin using health workers. But health workers are very few, they haven’t time to go round all the villages distributing ivermectin – it would compromise the rest of their health services.

“What is interesting in this approach – and I think this is the fundamental thing for people to understand – is that once you empower the communities to take care of their health, and you educate them properly on what they should be doing, they will actually do it.

“For example, people had always been organizing themselves to bury their relatives when they died. They do it themselves, they don’t ask health workers to organize that. It’s similar with these health interventions. Once you educate them about what they should be doing, they will organize themselves and do it.

“There is a great capacity in the community which we are not tapping! This is real, working primary health care,” said Ndymuguyeni.

“In Uganda it works like this. We have kinship structures. In a village you might find four or five such groups. So the community makes selection of the distributors along those kinship lines, and each kinship group has its own distributor. As a result this person doesn’t have so many to treat, and he doesn’t have to go long distances. Also he is treating his relatives.

“Some people have said that we should give incentives. But I ask a community distributor, ‘do you want incentives to give to your wife? To your brother? To your grandfather?’ He just laughs! And it is working well.

“The ownership is the critical thing. Elsewhere, the home management of malaria, for example, adopted the structure but not fully. You find in most cases that they appointed the distributors, and they were not selected by community members.

“The selection of the distributors is actually the key. If the community doesn’t appoint them you are going to get problems.

“For example, the distributor might be appointed by the village chief just because he is a friend, but this person might not be a good neighbour to you, stealing people’s chickens and potatoes – so you don’t want to allow them to come to your home.

“But when the community has collectively sat down and selected some people, those people are trusted, and they know that they are going to do the work efficiently.”

Elizabeth Hassan, Principal Investigator for the CDI study in Kaduna State, in North-Central Nigeria, reported similar success.

“The study went well, particularly in 2006 as we had a reasonable supply of materials: nets, antimalarials, and vitamin A, to both the study and the comparison arms,” she told RealHealthNews.

“But it became obvious that it’s not enough to supply the materials. The distribution method is crucial. In the comparison arm, the materials were given to the health system. But in the focus-group discussions and in-depth interviews, people in the communities said that they didn’t even know the materials were there.

“But in the study arms where communities were engaged and empowered, the distributors were told the supplies were available, they went to the health facilities to collect them, and they went back to the communities and announced to the people that distribution would be done. That’s why the results are good.

“It’s all to do with the CDI process. If the health conditions you are improving are seen as a problem, once you empower people, and they realise it is for their own benefit, it becomes a priority for the communities.

“To choose the distributors, usually you have two sets of meetings. The first is with the community leader and the elders in the community. You introduce

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the procedure to them and tell them the benefits, help educate them with posters, etc., and tell them what their roles and responsibilities would be, and the roles and responsibilities of the health service. Then you agree the date for another visit where you would meet the whole community and repeat that same process. And after that you leave them to select their own volunteers.

“Usually you suggest that they need people who are resident in the community, who have been there for some time, who are honest, hard-working, and willing to work for the community. Then you leave that decision for the community to take.

“There were more males chosen than females. Some communities picked people who were already distributing ivermectin, because they said they had experience; others selected entirely new people. Some were young, some older. They chose individuals, people they respected, people they knew could deliver.

“I thought that this would succeed, given the years that we have distributed ivermectin this way. But I didn’t really expect what I saw when I went to the communities with the distributors to see the antimalarials – it was very, very gratifying and fulfilling.

“Because when we started we made a baseline study and asked the communities what their priorities were; and malaria came up very high. So for once we’ve been able to meet the needs of the communities. That is a major achievement.

“The way it works is that the distributors go to the next level up. The communities are supposed to provide transportation. In some communities people volunteer their bicycles, or their motorcycles, for the volunteers to go and collect the drugs.

But the distributors get no payment for this work. So why do they do it?

“Some of them come out and say categorically we do it because we want to help our community. They say ‘we know this community has a problem with malaria, and we want to help solve that’. Sometimes you hear people say, ‘Oh, my community doesn’t give me anything, but they pray for me’. Sometimes they say that if when they are distributing they come to houses where people are eating, they offer them food.

“It also gives them some respect, and in the past we’ve had volunteers who because of their role in distribution of ivermectin have become councillors and politicians, they have become so popular!

“The communities know best who is reliable, who is going to deliver... It’s often people who are already playing a key role in the community.”

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“Distributors by kin group, as in Uganda, would make it much easier – we haven’t had that yet in Kaduna. It’s a matter of numbers. We are trying to get them to nominate as many people as possible, so the workload will be reduced.

“There was a fear that it would make ivermectin coverage fall. But this whole study has shown that this is not what happens. The coverage even went up. For me that is very gratifying.

“And that should also interest donors, partners and programme managers [to APOC] – that we have something that will help us sustain [ivermectin] delivery. Because most of the communities have been distributing ivermectin for 10-15 years, and the signs and symptoms of disease are gone, so you really need something to keep them interested.

“ivermectin distribution went up, because it is the communities’ first contact with community directed treatment, so the communities knew that if they responded to that better, a lot of their cares in terms of other diseases would be taken care of too.

“They even said it to us ourselves. One woman said to us, ‘You’ve given us river blindness control drugs, now you are giving us antimalarials that really help our children in this community, and you are also providing vitamin A that prevents blindness. We are very pleased about it’.

“So the programme is generating enthusiasm, and that was what bothered us in the first year, at our debriefing meeting, because we had built up this enthusiasm – but the supplies were not there in the health system. So the critical factor, the supplies, have to be there.”

Hans Remme of TDR, who managed the initial studies on ComDT for onchocerciasis in the 1990s, told RealHealthNews: “It’s quite a breakthrough.”
The study was conceived to solve a dilemma, he said. “ComDT was working so well [in delivering ivermectin], there was a lot of interest in using it to help health care in Africa by applying it to other diseases. On the other hand there was concern in the oncho community that this would overload the system. So we needed to discover the limits.

“Before we began this study, we had a lot of discussions with other disease programmes, countries and so on, on what really needed to be researched. And after long discussions, we basically came to the conclusion that what we wanted to find out was how complex we could make ComDT.

“Complexity we defined in two ways: one is the complexity of the different interventions. Ivermectin, and albendazole for filariasis are quite similar. Praziquantel for schistosomiasis is maybe a bit more complex; vitamin A, nearly the same thing.

“But then we saw at the country level much more interest to go far beyond just using this for mass treatment. Countries were seeing this more and more as truly an extension of their primary health care system. So we were led to look at other interventions, for things like malaria.

“Also we had information coming from communities – they said we like ComDT, but please do it for malaria. We heard malaria, malaria, malaria.

“So we selected five different interventions to test out in real life. We are staying for the moment where there has been experience, where there are ongoing ComDT programmes. And to that we added one intervention very similar to ComDT, vitamin A; one more difficult, mass distribution of bednets, involving behaviour change; and then two interventions in the direction of case management – home management of malaria, and DOTS for TB.

“The selection was of things that are already there at community level. ARTs for HIV/AIDS, for example, were not there. What we are talking about is taking an existing programme, and putting the community in charge.

“The community takes it very seriously, and has full ownership and direction. Many other community interventions are actually external programmes, using one or two community members to help with their programme. The real difference here is that the community decides how they want to go about it.

“The communities decide who are going to be the distributors. I think that is the critical thing. Because the communities know best who is reliable, who is going to deliver... It’s often people who are already playing a key role in the community.

“It tends to be more males that females. At one point we tried to improve the gender balance, but the women said we already do all the work here, and now you want us to go house to house and deliver the drugs! That was an external pressure which we don’t impose any more.

“This becomes a kind of extension of the health system, which has to provide once a year all the drugs the distributors need.

“One thing that comes up very much in discussions is the question of incentives... Different programmes [outside APOC] have different approaches... We really insist that the communities discuss the issue of incentives, and make up their own minds. The distributors are going to be doing all this work for them and it’s the communities’ responsibility to take care of.

“If they do decide on an incentive, it’s usually not monetary, but in kind. But most people say they really do it because they are keen to help their community. And of course it also boosts their own morale and status.

“The problem comes when other programmes offer financial incentives. That creates trouble,” said Remme, “as the ComDT distributor sees someone doing less work for another programme and getting paid. So we are now trying to get some agreement and standardization among programmes.”

TB is also proving to be more of a problem for CDI than the other diseases. Detection rates doubled in the study areas, but DOTS treatment did not go up. Distributors may have been affected by the widespread prejudice against TB patients, and fear of catching TB. Some asked for vaccinations before they would enter patient’s homes. So for improving DOTS delivery it may be that extra measures will be necessary.

However, according to Elizabeth Hassan, more time is needed to be certain of this because DOTS treatment lasts eight months. The whole study will be reported early next year.
Shopkeepers to deliver health to Africa

Franchised shops are creating community-level PPPs to deliver health products to the poorest in Kenya. Copied throughout Africa, they could provide and sustain a million new health workers, a champion claims.

Liza Kimbo is Kenya country director of CFWshops, “Child and Family Wellness Shops”, an extraordinary commercial concept for delivering pharmaceuticals and other health products to the poorest of the poor. It involves social marketing, but through the concept of franchising – renting the right to open a CFWshop, on a standard model and design, to local entrepreneurs, a concept similar to selling health like McDonald’s sells hamburgers. Research on this and other implementation initiatives is essential.

Could subsidized health shops work where the health system is weakest? Child and Family Wellness Shops in Kenya claim to be able to deliver cheap health care, parallel to the health system, with good-looking, standardised “chains” of shops selling health like McDonald’s sells hamburgers. Research on this and other implementation initiatives is essential.

>RHN: What an extraordinary idea, Liza. Can you tell us how you came to this? How did it begin?

LIZA KIMBO: About 1999 I met with a gentleman called Scott Hillstrom, who is an American philanthropist and has been donating to medical needs in Africa for many years. He had come up with the concept of delivering basic essential drugs and services at the village level, by working with community health workers and providing them with all the technical support that they would need in order to set up sustainable outlets.

Meanwhile, I was working with pharmacies in downtown Nairobi and was well aware of the real needs of our people – they were finding drugs unaffordable. So Scott and I got together and set out to open the very first CFW outlets in the central part of Kenya. We opened 11 of them in the year 2000 and we have been growing the network since.

>RHN: We also have here Jane Kengeya-Kayondo, who’s coordinator for implementation research at the Special Programme for Research and Training in Tropical Diseases (TDR). Jane, what’s your initial perspective on the CFWshops idea?

JANE KENGEYA-KAYONDO: I really like this concept. The realities of life are that kids who fall ill will seek treatment in their homes, using leftover drugs in their houses. And we know that most kids will die in the villages. They will not have reached hospitals or even health centres. In fact, in studies at the end of 1999 we found that in some countries 80% of kids will have died in the village without having come in contact with a trained healthcare provider.

So this is an excellent concept, because at least it gives hope that this enormous number of kids who are dying out in the boondocks, where the current public health services are not reaching, will have a chance of treatment.

>RHN: Liza, tell us what’s special about this franchising method. You’re bringing a business perspective to health for the poorest. This is an extraordinary approach. It’s a new kind of mind coming into this problem. Tell us your concept.

LK: It is a business approach, because we believe that if a health worker is in a position to run a successful business in their village, in the area where they come from, then that makes health care sustainable. They can build their business. They are fully employed and their community gets to know them as their provider of not just basic drugs, but also advice for consultations and for treatment and for follow-up. They are the “go to” person in the community.

When we looked at a lot of donor-funded initiatives in healthcare, we saw a lot of the idea of donating products, even of building clinics in some cases. The funds come in, the donor provides the care for a short period of time – but then they go away and, invariably, these units tend to close down. You come back five years later and you cannot see anything.

This was the experience all over Africa. So we’re really looking at how to get something that is sustainable and that is why we went to the business world – because, invariably, the most sustainable units are [successful] business units and that is the incentive for the health worker.

We do not pay the health workers a salary. They make their own money in an independent business that they can grow – and when they’re good at it they reach huge volumes of people and they have
very good returns from their business. That’s why we use a business concept.

>RHN: But how in a poor community can someone manage to make a salary out of selling drugs?

LK: When we talked to a lot of the mothers and the caregivers that were walking long distances to health posts seeking care, we found that all of them were carrying a little money. In fact, our experience is that people will take whatever they have and travel the distance to seek care.

But if they wait too long before they seek the care, because of the distance they have to travel, because they’re afraid, they don’t know what is going to be the outcome when they get there, the cost turns out to be beyond them.

By the time they decide to go to the health centre the simple drugs, the simple interventions that could have worked — had their illness been caught early on — can no longer be used. Now because instead of, let’s say, the first line treatment for malaria, the child comes in close to a coma, they need a drip, and maybe inpatient care, and that is very expensive.

What we found is that the majority of people in the community are making a little money. What we need to do is protect them so that that little money they have is enough to cater for their health needs.

That means providing an outlet that is close to where they live [so they are treated early], where you provide good quality generic drugs that are as cheap as possible but, at the same time, of the best quality available; and that you have somebody in that outlet who can provide them good advice, so that they’re not taking one or two pills when they need several more, and also so they are not being asked to buy pills where they don’t need to buy any pills.

>RHN: I think that studies in many parts of the world would show that mothers would pay of the order of US$ 0.50 or so for chloroquine, for example, against malaria — whether it is effective or not. So that kind of money, I guess, is available to you. But why do they come to you and not the quack somewhere else in the village, or the shop that’s selling the wrong drug?

LK: The system that we set up is that, first and foremost, we carefully select the franchisees, as we call them, the owners of the outlets. We vet their qualifications. We ensure that they are qualified to run these outlets.

We started off in the beginning working with community health workers who had already gone through some training and who we provided with additional training. Today we work with nurses, nurses who are professionally qualified and can handle a much wider range of diseases and also products.

“Our franchisees are people who go out into the community to educate, to inform, to prevent disease…”

LIZA KIMBO

Then we train our franchisees also on basic customer care. And we train them on how they can go out to the community, and hold meetings in order to promote health.

So we see our franchisees not as your typical shopkeeper business person who stays inside their shop and waits for people to come and select a range of goods. Our franchisees are people who go out into the community to educate, to inform, to prevent disease as much as possible and to show people what products they can use, which we sell, that can also prevent disease.

So mothers of the children come to us because we’re willing to provide these additional services for which they don’t have to pay. They can come to us and just ask for advice and get a consultation for which they do not pay a thing and it’s only where they need a product that they will be offered that product.

>RHN: Clearly Liza you’re doing a great job — but you are inevitably very committed, and the world needs some research to give an objective perspective on how things are going. It would also be very useful, I think, to produce an independent body of evidence that you can use with a government, perhaps not in Kenya, perhaps elsewhere, so that the project might be multiplied in other countries. And I guess, you’d like to learn some things about your market and how you could improve your service.

LK: Absolutely.

>RHN: So Jane, at TDR you are doing some research on Liza’s project.

JKK: The research we’re doing with Liza’s project we call ‘monitoring and evaluation’, but it’s not just filling books and adding up the numbers. We really wanted to understand what is behind this concept, what are the perceptions of the shopkeepers, how do they see themselves, who visits the franchisees and who doesn’t.

Then we want to quantify in real terms what contribution is this making to illnesses in general, to malaria specifically but to all childhood illnesses, so that we can provide the proof of the concept.

Usually good concepts like these are taken on, and then, eventually, we find out on what evidence was this based. So we really want to be sure that this good concept is well monitored, is well evaluated and can be promoted on measured values.

We hope that this will help people who want to take on the idea, or who want to scale it up — because we’ll have a careful study of the process, scientifically documented, with careful proof of what it can achieve and what it cannot achieve.

We will have proof of the good values of it — but also the dangers, such as they are, because those are also important.

And then finally we will have a time perspective. If you implement this idea over many, many months what can you achieve?

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I think with these concepts put together we will have a good programme, which can speak for itself. I think, in the end, it shouldn’t be Liza to speak for the programme. It should be the evidence to speak for itself about the programme.

>RHN: What do you feel about that, Liza?

LK: I totally agree. It’s actually about the right time to come in now and look for that evidence, because we expect to learn several things. We expect to find out where we are succeeding but also which areas we would need to improve.

We talk to our clients and they tell us good things all the time. It would be good to also have independent verification and establish what are all those other things that we could be doing that maybe we are not doing, how can we have even greater impact potentially in the community, what is it that we think our franchisees are doing that they might not actually be doing. This will be very useful for us but especially also from the perspective of scale-up.

Already we have a number of individuals from different countries who have come to us and said this sounds like a really good programme, we would like to set it up in our countries. It would really not be right to begin to scale up an initiative where you do not have that evidence base.

>RHN: Liza, I understand that you have some products, for example artemisinin combination therapies (ACTs) for malaria, which are being provided free. This gives you no income stream. There’s nothing to buy. So the nurse or whoever is in your shop doesn’t get an income out of that. That’s a bit of a problem. How do you tackle that?

And, related to that, it’s well known that illness, and particularly long chronic illness, in a family can cause immense economic hardship. So there are many social insurance schemes being developed. Again, this is money that at present goes back to a central source, not the local source. How do you deal with those two issues?

LK: Well, Robert, this is an interesting issue and a conflicting issue. Kenya is losing close to 34 000 people a year to malaria. This is really a crime against humanity. It should not be happening and if we have a drug that is working it should get to every single one of these children. We should save lives.

So, on the one hand, we totally appreciate why it is that all the initiatives, the Global Fund initiative and the Kenya government, are going out to provide these drugs to the people who need them.

The concerns that we have, as an organisation, is that we have found that there is poor access to interventions in the communities. Very many people in Kenya, about 56% of the population, live an hour or more away from a health facility.

There’s also a need to improve the health systems throughout the whole prevention and care process, in addition to the provision of drugs. So our initiative has come from the private sector, addressing a real public health need for improving access at the community level.

As we discussed, the way we have done that is by ensuring we have qualified health workers running sustainable units from which they have to make a living.

So the provision of free product just needs to be carefully thought through, in order that it does not undermine the initiatives that are out there that are also trying to serve the communities. Beyond the product itself, the workers who are dedicating their time and their effort need to be compensated.

So what we’ve negotiated with the Kenya government on ACT provision is that we can charge a small amount, less than about 30 cents on the dollar, which is a consultation fee that goes to the client. The drugs will provided free at the outlet but clients will have to pay this small consultation fee. However they will not have to pay this fee if they go to the government centre – and we will put up posters in our units that say it is free at the government centre.

So this one of the interesting things that we want to see from this study – what impact does that have? Will the clients come or will they choose to go where they absolutely do not have to pay for anything?

JKK: Yes, this is an interesting experiment but, in a way, when you think about the way international and national and regional health is going, we’re going to have to work towards more of these private/public partnerships.

For me, I see this as a miniature experiment of a private/public partnership. Let’s see how it can work at the community level when you bring the strength of the private sector, you marry it with some of the resources of the public sector and you provide care to the people.

I think we need to look at it from the point of view not so much of ‘what can the individual get out of it’ but ‘how can we bring the private sector and the public sector together to make a difference’ at the community level.

If we start thinking of it in that way then we think conceptually. We think beyond the 30 cents, and I’m encouraging Liza and her team to start thinking like that. Because then we can have a message that others can hear that, really, the private sector doesn’t have to go it alone separately from the public sector. There will be a model.

Here is a possibility for how you can merge the two and work together, one bringing their values and strengths, another one bringing their own different values and strengths, having together a concerted effort. I think you have a good opportunity here for a private/public partnership of a different nature, in the community. It could very easily just be as prominent as the big names of PPPs that we hear if we can monitor it properly.
It is a very critical point that the community sees the brand, and recognises the brand for a particular level of service.

The consumer needs to know that ‘McDonald’s’ means X, and always X. It may, as it is today, mean that ‘McDonald’s’ means you get the cleanest washrooms if you’re on the interstate, and not necessarily the quickest burger and fries. But, for sure, when somebody is entering a McDonald’s they know exactly what it is that they are going to get there.

So it’s the same within the health outlet. It is a very critical point that the community sees the brand, and recognises the brand for a particular level of service.

We fully appreciate that at CFWshops, and are now in the process of developing the brand, so that it is well known as an entity which is accessible, where you can get good quality medication, where the prices are controlled, where we have inspections and supervision and where the owner is answerable to some bigger entity than just themselves.

> RHN: That’s going to provide a challenge also to the public health provider, isn’t it, to bring themselves up to a similar level?

LK: Yes.

> RHN: So it’s going to be a stimulus for better health care.

LK: Yes, absolutely.

JKK: Because it’s an opportunity.

> RHN: How is this funded? I guess, Liza, it’s not entirely through the money that comes through the village. There must be some other source of money that must subsidise some of the costs. And, Jane, who pays for the research?

LK: Our network is such that the franchisee at the village level can be supported. [To work] it must have a sustainable business that is profitable and pays her.

But there are, as you rightly point out, at the central level all the costs associated with establishment of this franchise with the technical support, with the training and delivery of the drugs to the outlets. We have those overheads that need to be supported.

We’ve been fortunate over the years to get several individual donors to help us get the idea off the ground. We’ve also been fortunate to get support from organisations like the Rockefeller Foundation, from Acumen Fund and from the International Finance Corporation.

Right now for the ACT experiment, we’ve got assistance from the Exxon-Mobil Foundation and we’re very grateful for that. However, our funding has been in dribs and drabs. It’s not enabled us really to be able to scale up to the extent that we would want to scale up and so we’re looking for some additional donors to come in to work with us to pick up what we will get out of the evaluation and really scale this up, not only in Kenya but also across Africa.

JKK: Robert, you asked a very important question because this area of implementation research is relatively new, and not so well understood. So we are taking every chance we get to communicate it so that people understand it.

The world is becoming really innovative now on how to enlarge the number of products, for vaccines, drugs, diagnostics and so on, creating mega PPPs with large amounts of money. We know that without these tools we can’t really do public health.

But Liza and I and you and others know that without these tools reaching the majority of the people who live way out in the boondocks, who don’t have enough money, they will continue to die.

Unless we can bridge this gap between having a good product and having it abundantly accessed by people in the shortest time possible we will not achieve what we want. But the funding for researching this area is piecemeal compared to the huge amount of funding that is going to producing the products.

The product development part is very visible, and it’s increasing its funding. But this part, delivering the product, is not receiving as much funding. Maybe it’s a question of how we communicate it. Maybe it’s a question of how we promote it. But somehow or another we are going to have to correct this imbalance if we’re going to make a difference.

> RHN: Liza, one last point that relates to the same phenomenon is that WHO recently estimated that Africa needs of the order of a million new health workers
of one kind or another over the next ten years to actually deliver the products that are in the pipeline and exist already. Of course we all know about the constant brain drain, the loss of health staff abroad. Is there potential for your approach to fill that one million gap?

LK: Robert, you know my answer’s going to be yes [laughter]. As Jane says, we need to have a forward thinking view. If we are developing products we have to be looking at how are those products going to get to the people who need them.

For example in Kenya 80% of the population is still rural based. If you look for all the health professionals you’re going to find them in the cities – or you’re going to find them leaving to other countries that can provide them with the kind of lifestyle that they should be having.

Our challenge is how do you get product to the rural areas where there are communities that are underserved – and the time to deal with that is now. We can’t wait until when a product is available and suddenly discover that we don’t know how to get it out there.

There have been successful initiatives. There are a lot of lessons that have been learnt that we can build up from. We’ve got the vaccination programmes. Those have been very, very successful. So what is it that we can pick up from the successful outlets, the successful ways in which we’ve reached people so we can ensure that those will be there ten years from now so we can build up on success?

I’m arguing that having our units, having the health workers where you need them in the rural area, will reduce the costs considerably of getting products to the people rather than having vertical set-ups. Without something like this every single time you want this product into the community you’ve got to create this vertical programme, this other vertical programme, and this other vertical programme ad infinitum. But there are other ways of doing it, and let’s start now. RW

**Summary**

With chloroquine no longer recommended, Africa desperately needed cheap, simple artemisinin combination therapies. The Drugs for Neglected Diseases Initiative, DNDi, is providing them as its first product. They will suit most – but not all – African countries. Director Bernard Pécoul tells RealHealthNews the story.

The Drugs for Neglected Diseases Initiative, a global health partnership created in 2003 by Médecins sans Frontières – with six major public research organisations – to develop useful drugs for the diseases of the poorest, has scored its first hit with a treatment for malaria.

In Africa hundreds of thousands of children die of malaria each year for lack of effective and practical treatment. DNDi’s artemisinin drug combination, announced in March, isn’t new, but DNDi’s unusual approach to drug development – starting first with real human need, based on the real experience of health care in the poorest communities – will make it a much more practical treatment, reducing loose jumbles of 24 different tablets to just three packaged doses. And it will be cheap.

**Bernard Pécoul, Director, DNDi:**

We have just launched the first product to be developed by DNDi – and many partners – to try to improve the management of uncomplicated malaria cases. The drugs are useful anywhere, but I would say the first target of this product is Africa.

The development has taken the last five years. It’s a co-formulation of artemisunia
with amodiaquine, so it’s one of the few artemisinin combination therapies recommended by WHO. It’s already used, in a loose combination, in many countries. Some 20 countries in Africa have selected this combination as a first line treatment. But for the time being they use loose combination, so a tablet of artemunate on one side, and tablet of amodiaquine on the other side.

> RHN: So, what made you decide to develop this, since it was already on the market? Is it a new formulation, a new package?

BP: It’s more than packaging. Because of rising malaria drug resistance, in 2001 WHO recommended countries to switch to the use of artemisinin combination therapies (ACTs), from the classical, cheap chloroquine. But the selected combinations for Africa were very few. One was artemunate with sulfadoxine-pyrimethamine [SP], but this is impossible to co-formulate because it’s three days artemunate, followed by one day of SP. The other combination was Coartem – artether and lumefantrine, the product developed by Novartis. And the third combination in Africa was a combination of artemunate with amodiaquine. However this last combination was not co-formulated, so it was large number of tablets. For an adult, for example, it was four tablets a day of artemunate and four tablets a day of amodiaquine, twice a day for three days. So 20-24 different tablets to treat a crisis of malaria. So a lot of different tablets, with a risk of patients taking one tablet and not the other.

So the recommendation from WHO was to try to develop a co-formulation. We were also pressed to do it by Médecins Sans Frontières (MSF) [the founder of DNDi], because MSF was one of the main users of the combination. So we entered into this project in 2002. We started with pharmaceutical development. It was not easy to co-formulate, for a very simple reasons: when you put artemunate with amodiaquine, one of the products produces water. That dilutes the other one, so you cannot maintain a good level of both drugs in the combination. So we were obliged to look for a special technology, what’s called a ‘bi-layer technology’, to separate the two products.

The second objective was to reduce the number of tablets, and ideally to have only one tablet a day for three days.

And the third objective was to have a formulation for children, for different ages.

> RHN: That was a lot of objectives! Did you also have to do clinical trials?

BP: The first challenge was the pharmaceutical part, because of the water problem, because of the reduction of the number of tablets. So we worked with several groups, one the University of Bordeaux, one the biotech company Ellipse, and later on, one pharma partner to test the capacity to scale up production. So the first step was to have tablets. And then, yes, you need to do some clinical studies. So we developed a large clinical study in Burkina Faso, involving 750 children. And, and we collected some other data on bioavailabilities. So we did a series of studies to have a package ready for registration.

In parallel, we looked for industrial partners to be in charge of the completion of the dossier, to be in charge of registration, to be in charge of distribution, and in charge of the promotion of the product. So we signed the first agreement with sanofi-aventis at the end of 2004, as the first industrial partner to complete the registration file and the distribution of this product.

When I say sanofi-aventis is first, it’s because they’ve accepted the non-exclusivity on this contract. So they will be the first to register and produce, but the dossier will be in the public domain.

> RHN: You started this when?

BP: We started 2002 with many partners. TDR was one of the key partners. It’s taken five years.

> RHN: Let me ask you just briefly, a personal question – what is your background?

BP: I’m a medical doctor, and spent 20 years with MSF in many different places. During the 1980s and 1990s I was in management in MSF. I was the Executive Director in Paris. And then I moved to Geneva to set up our international campaign on access to essential medicines.

> RHN: I ask because what you’ve described for your new product is a massive management problem, isn’t it? Apart from the technical problem, there are so many components to it.

BP: Yes. But we were really lucky to attract, right at the beginning of the exercise, a very competent project manager – someone coming with 30 years experience of management in industry: Jean-René Kiechel. He’s still the project manager today. But I have to say it’s a pro bono contribution – because he was recently retired from industry, and he spent the last five years co-ordinating this project between its some 15 or so different partners.

> RHN: So he made a big contribution to getting this done.

Continued on page 12
BP: Yes, in managing the project steps and coordinating the different the different steps.

>RHN: But tell us more about the technical solution. What was the technical trick that finally made it possible to combine the two components?

BP: The first was the bi-layer technology, just to separate the two. But the second technique was to reduce the number of tablets, as well as the size of the tablet to facilitate doses for children. So it was a kind of compression system. This is where the biotech company played a very, very important role.

And the last technique, also important, was the packaging, because another challenge was to be sure that the product would be stable in tropical conditions.

So of course, the nature of the product was important but also the packaging was important, so we end up with what we call a ‘double alu’, a double aluminium packaging to get a reasonable shelf life in tropical conditions.

>RHN: And, of course, the bottom line is the price. What’s the price?

BP: Of course the price was another big issue, so yes it was another objective of this project was to try to reduce the price for the number of patients. So we wanted to have a partner accepting to work at cost. It could be at cost with a small margin – we were open to that – but we felt that the price should very close to the real cost of the product. So sanofi-aventis accepted this condition.

So the target price per treatment is less than one US dollar for adults, under 50 US cents for children under five years old.

>RHN: That is amazing, compared to the existing ACTs.

BP: Yes, it’s a reduction. But one reason for that, of course, is that while artesunate is the same price as in other ACTs, our companion drug, amodiaquine, is much cheaper than the companion drug used in Coartem, lumefantrine.

>RHN: What exactly did the clinical trials test?

BP: The pivotal study was a Phase Three study of the co-formulated product versus the loose combination, in 750 cases of clinical malaria in children from six months to five years old in Burkina Faso.

>RHN: So what were the numbers?

BP: The level of efficacy is over 95%, which is quite good for malaria products. That was the objective. And in terms of tolerance, the side effects are comparable to the side effects observed in all malaria studies. You cannot have zero side effects with malaria, because after treatment you have a mix of symptoms linked to the disease, with symptoms that could be the consequence of the treatment. It’s the same for all malaria treatments.

>RHN: Directly or because of the killed parasites?

BP: Both. Typically you have fever at the beginning, after that you have vomiting – the classical symptoms that you find with the disease. The fever disappears rapidly with artesunate and amodiaquine. But some vomiting was observed in some of the cases.

>RHN: What about adults?

BP: The non-co-formulated combination of artesunate and amodiaquine, the loose combination, has provided a lot of data [for adults], in terms of tolerance and toxicity. We collected this data to bring into the registration pack.

>RHN: And what’s the position of WHO on this drug?

BP: In January 2006, WHO produced formal malaria treatment guidelines, four years after the official recommendation for ACTs, which already recommends the use of this drug. It was considering the existing loose combination, but it also mentioned that as soon as the co-formulation would be available, then countries should make a complete switch to the co-formulation.

However we have to be clear. Some countries in Africa are not candidates for this drug. Because you need an assessment of the efficacy of the amodiaquine [on the malaria parasites in that country] in order to recommend a combination of effective drugs. In some countries, amodiaquine is not sufficiently effective.

So, particularly in some countries in the eastern part of Africa, today I would not recommend the use of this drug. The situation could change later, but today, with the data that is available, I think it’s better to use another regimen. But in other parts of Africa, a large part of Africa, it will work, and 20 countries have decided to go with this combination as the first line treatment. The issue for them will be to switch from the loose combination to the co-formulation.

>RHN: What will the co-formulation mean, then, to, to a minister of health in one of these countries?

BP: I hope that for them the main advantage will be that it will make it easier to implement a malaria strategy at national level. You need to involve thousands and thousands of people, because you need to treat – depending on the size of the country – one million, two million, three million cases, even five million cases in some countries.

So I think they will find that they have a product that is extremely easy to manage, because you have just three different dosages, for each category of age. And a regimen of one tablet a day for three days, I think it’s much easier to promote, to explain, to use, and to distribute.

>RHN: To store, as well?

BP: To store, because we’ve been working a lot with sanofi-aventis to try to improve the packaging, so they are preparing a blister pack for different categories. And packaging of 25 treatments in order to facilitate the logistics for the clin-
ics, and so on. We have tried to think about this kind of issue, to facilitate the distribution.

RHN: You don’t make a profit out of selling this?

BP: DNDi is not for profit, so I think it’s clear for DNDi. Also in this case sanofi-aventis has accepted this for all the public sector, international organisations, NGOs, and the not-for-profit sector within the private sector. They are promoting what they call the “Impact Malaria” project. So they are trying to give access to this low cost product also to some private companies and pharmacies.

RHN: But still at the same price.

BP: Still at the same price. So they’ve already started Impact Malaria in three countries, but they have the ambition to extend to other countries, to bring this, at cost, to private pharmacies.

RHN: So the marketing will be done by sanofi-aventis, will it?

BP: Yes.

RHN: What results do you hope from this, if we think of the numbers of malaria cases, and numbers of malaria deaths – which is an extraordinary high figure in Africa.

BP: Yes.

RHN: What impact could this have?

BP: Well, it’s difficult, but when we started talking with WHO, the target population for this product was somewhere between 50 million cases to 100 million cases a year, maybe more.

RHN: As for deaths, they are mostly in young children, aren’t they?

BP: Yes. So the advantage of creating something for children is that you will address this issue. Because today, the use of artemisinin combinations for children today is quite complicated. You have to cut the tablet, so it’s not easy to use.

RHN: What proportion of malaria deaths occurs in that first six months, where this combination is not indicated?

BP: Few, because in the first six months most of the children are protected by the antibodies from the mother. So I think the most affected population is six months to five years.

RHN: So you have a formulation for that period now.

BP: Yes. It’s not a syrup, so it’s not exactly a paediatric formulation – because a paediatric formulation is something that can be absorb directly. But it’s a small sized tablet that small children could take if the mother just squashed the tablet into water or some liquid food – a soup, or something like that.

RHN: Now you’ve done an enormous amount already, but what about getting the drug to the end of the track? How do we make sure that once we’ve got we’ve got a good product, and it’s accepted by the government, that there are implementation processes that get it to the people who need it?

BP: It’s still a big, big challenge, I think we’ve taken some steps in the right direction, to reduce the price, to make the product much easier to use, to make something adapted to children. That facilitates a process.

But after, of course, you need to implement the strategy at a village level. But, but these things are connected because if you have something very easy to use, you can much more easily think about using community health workers to implement the strategies.

RHN: Sure.

BP: Also training the mothers at this community level becomes much simpler when you have an easy strategy. When you have a very complex strategy, it’s difficult to explain.

RHN: Yes, the home management of malaria, for example, was tested in Ethiopia, in fact, by, by TDR, and proved to be extremely successful. But, unfortunately, that was the pre-artemisinin days...

BP: Yes, and they, and they tested mainly with SP, which is only one dose to treat. But, unfortunately today, SP is not effective in many cases. So you cannot comment.

Our coformulationne tablet once for three days so it’s still quite simple. So it will be very interesting to have implementation at this level. I think it’s the next challenge. So one of our challenges is to involve more partners in implementation.

But we also must document a little bit. We have to be very careful that the product is being used properly, that we continue to monitor the efficacy, the toxicity, and the tolerance.

RHN: Do this story illustrate something that DNDI will be able to bring to other diseases?

BP: I hope we’ll use this model for the rest of our portfolio. Our coformulation is one tablet a day for three days so it’s still quite simple.

RW

This interview continues on line at www.realhealthnews.net where Bernard Pécoul introduces the next DNDI products in line – artesunate mefloquine, under development with partners in Brazil, and a plan to simplify DOTS for TB.
Some TB tests only 1% effective

Simple dipstick tests for infectious diseases are multiplying rapidly. But how good are they? Field trials are few, and results disappointing. Countries should press for more research and proper regulation.

SUMMARY

Simple, accessible and effective rapid diagnostics tests for the major diseases of developing countries could cut unnecessary treatments, reduce the development of drug resistance, and save millions of lives. But tests are under-researched and unregulated – so not a single rapid test for TB, for example, can be recommended. More field trials and proper regulation are the answer.

Pharmaceuticals are highly regulated worldwide – with new entities requiring rigorous clinical research that pushes their cost (say companies) towards US$ 1 billion. But amazingly, in many countries anyone can develop a ‘diagnostic’, make a claim to its effectiveness, and go ahead and sell it.

At the same time, biotechnology is making testing easier and more accessible, using “dipsticks” that change colour when they detect pathogens in whole blood. If they work, they can ensure appropriate treatment even in remote areas without electricity. So the numbers of rapid diagnostic tests are multiplying rapidly.

In principle, good and simple tests can save lives, pharmaceuticals – and health budgets.

For example, a study funded by the Bill and Melinda Gates Foundation showed that diagnostics of 95% sensitivity and specificity, backed up by treatment, could save 1.8 million lives a year from malaria, and prevent 400 million unnecessary treatments (see page 17 for more examples).

Early diagnosis and treatment can also reduce the risk of a patient developing long-term complications – and for diseases such as tuberculosis, sexually transmitted infections (STIs) and HIV, they also reduce further transmission of disease to other members of the community. And over the long term diagnostics and the consequent reduction in misuse of important pharmaceuticals can reduce the development of drug resistance, like that of the malaria parasite to over-used chloroquine.

However existing rapid diagnostic tests have a limited shelf-life of six months or less in tropical climates, cost from US$ 0.50-1.00, are largely unregulated, the published literature gives little guidance to their value, and many are failing in the field. So better tests need to be developed, and they all need independent testing where they will be used.

So Rosanna Peeling, head of diagnostics research and development at the Special Programme for Research and Training in Tropical Diseases (TDR) tells RealHealthNews.

Out of nineteen rapid TB tests investigated, “none could be recommended”.

ROSANNA PEELING

RHN: In much of the developing world, are diseases mostly diagnosed by their symptoms?

ROSANNA PEELING: Yes, by clinical presentation... There are some laboratory tests. But because in the developing world there aren’t very many laboratory facilities.

For example, the WHO recommends the integrated management of childhood illness (IMCI), where health workers look for certain signs and symptoms in the patients, and then use broad spectrum antibiotics to cover major causes of those symptoms. And for STIs the WHO advocates ‘syndromic management’ to compensate for the lack of access to laboratory testing facilities.

So, a lot of the diagnostics that had been developed up to the 1990s are mostly for developed world use...

RHN: …except for microscope work to detect parasites, for example. But of course not every village has a microscope! When is it medically dangerous not to know exactly what someone has got?

RP: There are two scenarios. One would be where infections cause no symptoms at all and yet the consequence are very serious. So for example, most people who acquire syphilis may have very transient or no symptoms.

Women who became infected with syphilis during pregnancy, or before they became pregnant, would have no idea that they had the disease.

Then what happens is that the infection is passed on to the baby, and the woman either miscarries, or that the baby is still-
born, or born with congenital syphilis – which has very serious consequences, lifelong.

The magnitude of the problem is that, for example, in sub-Saharan Africa, half a million babies die a year because of congenital syphilis.

This is simply because we fail to screen the infection in women in pregnancy.

The other scenario is that you or your child may appear ill, but your clinical presentation is very non-specific. An example of this would be malaria, or children presenting with fever.

So, in Africa, a child presenting with fever in a malaria-endemic area would be treated for malaria, and if the child also has shortness of breath, you would treat for both malaria and pneumonia.

But in Asia, a child presenting with fever could have dengue fever, they could have malaria, or could have several other causes of fever...

›RHN: And in each case you’d do something different to save the baby.

RP: Yes, and because the broad use of antibiotics is not a good thing, as it can lead to drug resistance.

Also, in a malaria-endemic region, malaria drugs are becoming very expensive, because the parasite has developed resistance to all the cheap drugs. And so we can no longer afford presumptive treatment of every child presenting with fever.

So, now we have to really target the treatment, but how do you do that? What indications can you use? In areas where there is no microscopy, there is no alternative. But you can lose a child in a few days from malaria.

›RHN: But with modern technology, particularly with genomics, it must be becoming easier and cheaper to do these diagnoses.

RP: For malaria alone, there are 40 companies making dipstick-type tests, and in principle these tests work very well. All you have to do is to put a drop of whole blood onto the dipstick, and then add a drop of reagent, and you watch this blood migrate across the stick.

And when you see two lines, that means the test is positive. When there’s only one line it means that the test is negative.

›RHN: It’s a simple concept.

RP: 80% of rapid tests on the market, for whatever disease, are of this type.

›RHN: You say 40 companies are making such things for malaria, but there’s no regulation. So you decided to test them?

RP: Yes. We decided to develop an evaluation scheme to systematically evaluate the performance of these tests, and not only the sensitivity and specificity, but also the user friendliness.

We asked: are the tests simple to perform? Are the instructions clear? Is it easy to read the line?

And one of the key things is that if this test is to be performed in a peripheral clinic where there’s one health worker who’s looking after many patients, you
may not be able to wait the 20 minutes for the lines to develop.

Sometimes you may be busy with another patient or with other things, and then you have to come back an hour later, or two hours later. Would the test still give you the same result? With some of the tests, after one hour or two hours all tests would come back positive - because they absorb moisture from the air and then all the lines would show up.

So, we have to do these sorts of practical evaluation.

>RHN: This is a very interesting situation in medicine for developing countries – it’s a reversal of the usual case. You’re not short of products. The products are all over the place. But you don’t know how good they are!

RP: Yes, at least for some diseases. For other diseases like sleeping sickness, there are hardly any products out there on the market.

And also the current test for sleeping sickness require a spinal tap to stage the disease to give the correct treatment, because the treatment for acute infection and the treatment for the disease that has gone into the neural system are different – and both of them are toxic so you need to be sure that you’re giving the right drug to the patient.

We really need a type of diagnostic that uses a less invasive specimen to replace the need to do a spinal tap.

It’s similar for visceral leishmaniasis, where you have to do a splenic aspirate, or a lymph node biopsy. Presently, the gold standard is the splenic aspirate – but it carries with it a mortality of 1:2 000.

The governments of India, Bangladesh and Nepal declared that they’d like to eliminate visceral leishmaniasis from the Indian subcontinent, at the 2005 World Health Assembly. So, if you think in terms of elimination, and you’re going to use diagnostics widely to find cases...

>RHN: ... A lot of people would die just from the diagnosis.

Dengue outbreak - a lesson learned

A country faced an outbreak of dengue, and there was no time for investigating which test kit would be best, Rosanna Peeling told RealHealthNews. “The tests were marketed as 100% effective, so the ministry just looked at all the products and said, OK, we’ll take this one.”

Then they found that they weren’t picking up many cases. “So they sent the test kits to a university lab that had a big name in dengue research, and they found that the tests they ordered were really poor.”

It was only then that the ministry realised that they should have put into place a proper evaluation mechanism. RW

RP: Exactly. So, there is the impetus for us to really find a non-invasive way, or a less invasive way of diagnosing visceral leishmaniasis.

For different diseases we’re at different stages. Our three areas of focus are test development, test evaluation, and then application – doing demonstration projects on the feasibility and utility of these tests.

For African sleeping sickness, leishmaniasis and tuberculosis we’re mainly working upstream in terms of facilitating better tests to be developed, and evaluating whatever tests there are on the market.

But for schistosomiasis and dengue, our work is mainly evaluating existing tests with a little bit of redevelopment if certain tests need improvement.

For malaria and STDs we’re way downstream in terms of doing demonstration projects on cost-effective strategies to increase access to effective diagnostics.

For syphilis, we’ve actually included seven tests with acceptable performance into the WHO’s bulk procurement scheme so that member states can have access to quality-assured tests at negotiated prices.

>RHN: In your trials, did any of the syphilis tests come out badly?

RP: Only one, and, and it didn’t do that badly. And I think there is a reason for that. Many of these tests were developed for blood-borne infections. I think manufacturers who want to get that blood screening market try harder.

>RHN: You said there were about 40 companies making tests for malaria – what spectrum of quality did they have?

RP: Some of the publications show sensitivity as low as 30-40% and some are in the 90% region, so there’s a whole range of them.

But the problem with relying on published data is that a lot of the studies are done in not very well-defined populations, so that you don’t really know whether the test was evaluated in the populations of intended use.

>RHN: Are they producer-sponsored tests we’re talking about here?

RP: Yes, normally.

>RHN: So there’s bound to be some bias!

RP: Well, maybe it’s unfair to always say that there would be bound to bias! I always say they’re more prone to bias. Sometimes it’s not so much the manufacturer’s fault as that they are trying to market their test for every kind of population.

We try to define in what setting these diagnostic tests should be used, and in what setting shouldn’t they be used. Whereas for companies, all they want is to push their test. So sometimes it leads to a lot of very misleading data.

On top of that, companies have varying budgets for doing these sorts of evaluations. So, we did a survey a couple of years back to ask companies how much money they actually spent on evaluations, and the range is from some US$ 2000 to US$ 2 million.
The company that spent US$2000 actually evaluated their test on 15 patients... and the test is sold. But that wasn’t a malaria test.

Recently a company sent a syphilis test to me for evaluation, and the claim in the product insert is 100% sensitivity, and 100% specificity. I said, wow, this is great, this is exactly what we need! So, I phoned them and I asked how the evaluation was done.

They said, well, we contracted it out so we don’t really know. And I said, how many patients? Oh, over 100 patients. I said, how many were positive? Three!

So this is the kind of data you find in the literature. So another thing that we ended up doing this past year has been to write and develop recommendations on how to design and conduct diagnostic evaluations, because there are just no standards out there.

We’ve done that for malaria, and we have done that for sexually transmitted infections, for syphilis, gonorrhoea, and chlamydia.

> **RHN:** Among all the diseases, which one came up worst in, in the evaluation of all the tests?

> **RP:** Tuberculosis.

> **RHN:** And how bad was that?

> **RP:** Some tests had sensitivities of 1%, if that’s possible [laughs].

> **RHN:** You mean in just 1% of the positive cases they actually gave a positive...?

> **RP:** Yes.

> **RHN:** Wow. And what was the best?

> **RP:** Out of that evaluation, the best sensitivity was around 60-70%. Not good enough.

> **RHN:** How many tests did you look at in TB?

> **RP:** Nineteen, and none could be recommended.

> **RHN:** What’s making the tests so bad?

> **RP:** Well I think it’s because the test developers don’t evaluate them in the right population – where they don’t have good access to good culture facilities, microscopy etc... And also because of the lack of regulation – they develop something and they put it on the market.

> **RHN:** And you have to think of other practical criteria too.

> **RP:** Yes, for example the tests should have long stability – because when these tests get shipped to a country, they could sit in customs for six months, and then, after they clear customs, and then it still has to be sent out to the regions.

So if you have a test with a year’s stability, or six months, it’s certainly not enough. A year, barely, because by the time it gets to the regions it may only have three months’ viability. And then for some countries, of course, the bottom line is price.

[Lives or DALYs to be saved by diagnostics (per year) – some examples]

<table>
<thead>
<tr>
<th>Disease</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Malaria</strong></td>
<td>A rapid test with 95% sensitivity and specificity and minimal laboratory requirements could save 1.8 million lives and prevent 396 million unnecessary treatments</td>
</tr>
<tr>
<td><strong>TB</strong></td>
<td>A rapid test requiring no laboratory infrastructure, with 85% sensitivity for smear-positive and smear-negative cases, and 97% specificity, could save 400 000 lives</td>
</tr>
<tr>
<td><strong>Acute lower respiratory infections (ALRI)</strong></td>
<td>A rapid test for bacterial ALRI with 95% sensitivity and 85% specificity with greater treatment access and minimal laboratory requirements could save over 400 000 lives</td>
</tr>
<tr>
<td><strong>HIV/AIDS</strong></td>
<td>A rapid test with 90% sensitivity and specificity and minimal laboratory requirements could save 180 000 DALYS if 5% of the population had access to ARTs, rising to 2.5 million DALYS if 100% of the population had ART access</td>
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<tr>
<td><strong>Syphilis</strong></td>
<td>Screening of antenatal women with a test that is at least 86% sensitive, and 72% specific, with minimal laboratory infrastructure, and has either everyone returning for their results or everyone being treated, could save over 138 000 lives and prevent 140 000 stillbirths. If no laboratories were required the test and treatment could save over 201 000 lives and prevent 215 000 stillbirths</td>
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Countries also always ask for technical assistance when they purchase tests, because we give them training modules on how to train people to use the test safely.

When you roll out these tests to remote areas where they’ve never taken a sample, they’re afraid, especially in Africa, of HIV transmission, etc. – so doing it safely at a health post, how do you dispose of the test, how do you dispose of the blood, these are issues.

> RHN: Well, these are important questions...

RP: Yes, yes, and they do affect the practical choice.

> RHN: Broadly, many of the current rapid tests have serious weaknesses – though some, for example the antibody tests for syphilis, seem stronger. In developing improved tests, what would be the most important challenge to tackle?

RP: Right now for us it would be to increase sensitivity – while keeping the test accessible. Remember there are wonderful tests that you can do for TB, dengue, STIs and so on, in sophisticated laboratories; but they require expensive machinery, electricity, and highly trained staff.

> RHN: So we really need to increase the volume of R&D on developing new tests that combines good performance with ease of use in primary health care settings – and then conduct field trials in developing country circumstances.

RP: Oh yes. Getting the right diagnostic tool is only half the battle. The other half is getting the testing done properly in the field and ensuring treatment.

> RHN: To what degree do you think you need to scale up field testing and comparison of tests? By two, by ten, or what would you say?

RP: I would say by ten! At TDR we are now dealing with diagnostics for nine diseases with five professional staff. And TB and malaria are really huge diseases.

> RHN: So you could do with other partners.

RP: Yes, we already have about 30 partners in developing countries, like the Tanzania National Institute for Medical Research (NIMR) and the Kenyan Medical Research Institute (KEMRI). We also collaborate with Foundation for Innovative New Diagnostics (FIND), the Program for Appropriate Technology for Health (PATH) and a number of tropical disease research institutes in the developed world.

> RHN: But you need to scale up in terms of numbers of people and also budget?

RP: Yes. But the Gates Foundation has given a lot of money for TB diagnostics, and are providing some funding for our work on STIs and malaria; and FIND has some funding for African trypanosomiasis – so donors are beginning to recognize the need.

> RHN: In countries, in terms of health budget, would a diagnostic budget be a lot cheaper than treatment, in general?

RP: It’s a fraction, usually.

> RHN: So that makes it easier to get into policy.

RP: But for syphilis, for example, the treatment is also very cheap because penicillin is very cheap. And yet, if you don’t have the diagnostic you cannot even guide treatment. And so there the cost of the treatment is immaterial.

> RHN: May I ask you about the question of regulation of diagnostics? Is there any move towards tightening up regulation?

RP: Yes, part of our plan for next year and beyond is to try and help countries with developing capacity for the regulation of diagnostics.

We’re hoping for two things. First is that countries themselves would devote personnel and resources towards diagnostic regulation; and second, is that they would actually do what we call regional harmonisation of the approval processes.

In other words, we hope that if an evaluation were made in Tanzania, for example, then maybe all of sub-Saharan Africa countries could accept this data, instead of insisting the manufacturer go and do a study in their country to obtain country-specific data before approval.

So most people underestimate the power of diagnostics. So if there’s anything to be done about making the role of diagnostics better known, and how the research on diagnostics can lead to saving lives, it should be done.

But there’s no media pressure. When you see the headlines, it’s never about diagnostics. Diagnostics doesn’t cure anyone. Drugs, vaccines, are the end product of what people want. Diagnostics is neglected because its role is not really clear.

> RHN: And but who needs to know, to hear this story?

RP: I would say the disease control programmes certainly need to pay more attention. Countries need to pay more attention in terms of regulation.

> RHN: They need to be aware, actually, of how bad some of the tests they’re buying are.

RP: Yes, exactly.

READ ON

Diagnostics Research at the Special Programme for Research and Training in Tropical Diseases (TDR)
www.who.int/tdr/topics/diagnostics/default.htm

Improved Diagnostic Technologies for the Developing World – Nature supplement 2006
www.nature.com/nature/supplements/collections/npgpublications/diagnostics/index.html

FIND, the Foundation for Innovative New Diagnostics
www.finddiagnostics.org/about/ceo_message.shtml

PATH website for rapid diagnostic tests
www.rapid-diagnostics.org/index.htm

Malaria rapid diagnostic tests – WPRO website
www.wpro.who.int/sites/rdt/what_is_rdt.htm
Let's make health systems work

The Alliance for Health Systems and Policy Research will expand health systems science globally, and put it to work for policy-makers. Manager Sara Bennett tells RealHealthNews how.

The communication of research to policy is a little-studied art, and needs the synthesis of results by knowledge brokers, and testing in focused, country-level contexts, argues Sara Bennett of the AHPSR. Health systems research itself is also deeply contextual, and much more investment in multicountry studies is needed if we are to provide good evidence to policy-makers, she says.

RHN: Worldwide, there is an increasing interest among donors on communicating research to policy-makers. Do you think researchers should be encouraged to take this into their own hands, and promote their results?

SB: I think the focus on disseminating research findings and communicating them to policy-makers is important, but I think there’s a problem if you say each individual research project should be communicating to policy-makers….

We need to look more at knowledge brokers who have a role in synthesising the research evidence available, from within the country as well as from other countries, reflecting and adapting it to local country contexts.

RHN: One of your goals within the Alliance is to synthesise results in this way. Is this what appealed to you about the organization, when you decided to join as Manager?

SB: Absolutely, in that I’ve been involved in health systems research and the application of research to policy, since the beginning of my career; at the same time I felt, and other stakeholders in the Alliance felt, that for this agenda to be really successful it has to be owned much more by the users of health research than it has been to date.

I think this is quite a common problem with health research initiatives, that the researchers have a very strong stake, but the people who need to use the research have a much weaker stake.

So one of the things that we’ve been trying to do is to shift the Alliance a little bit from research and knowledge generation to appreciating that while that is very important, it is only one part of the process. You also need to look at how research evidence is synthesised, and how policy-makers and civil society organizations can access research evidence and use it in their day-to-day work.

RHN: In journalism, we’ve found a similar problem with the media, particularly in developing countries, in that we are getting an increasing number of science writers and broadcasters, but they seem to know very little about approaching the policy world.

So they are in good contact with their scientists, and with scientific results, and can explain them clearly, but they have little experience at all of dealing with the ministries. So I think there is a need for developing a culture of reporting that crosses that division as well.

SB: I think that’s quite relevant, because there is also a somewhat simplistic model of researchers on the one side, and policy-makers on the other, and then research being communicated to policy-makers who then make the decisions.

But in fact there is a whole set of different actors involved in policy networks, media being a very very critical part of that.

We were in a meeting recently, and the deputy director of health services in Ghana was saying that if the media cover a story, and the Minister sits up and listens, that really brings things to the policy table.

So I think it’s important to understand all of these different actors and organizations and how they interrelate.

RHN: Covering health policy and systems research globally is a large task. The goals of the Alliance as stated in your documents are extraordinary, but you have only 3-4 staff. Do you have the resources to do the job?

SB: Coming at the question in another direction, when we were working on our strategic plan there was some move to shrink our objectives to match the resources currently available; and a number of us resisted that. Because all our objectives are important ones – goals that the world should be trying to meet.

I guess a frank answer to you question would be no, at this point in time we don’t have the necessary resources or
staff to meet those objectives fully; but we need to put them out there, and demonstrate that they are important.

> **RHN:** You have a grant of £5 million (US$ 9.9 million) from the UK’s Department for International Development (DFID) – is that your main funding?

**SB:** DFID is the most significant single funder. Our total income is about US$ 3.2 million a year. This year [2007] we are projected to spend about US$ 4 million, because we’ve had a slack period and we have some money in the bank.

> **RHN:** And how are you dividing that cake, roughly?

**SB:** We have three objectives: knowledge generation, evidence-to-policy work and capacity development. We were striving to get a fairly equal balance between the three. In practice, for this biennium, capacity development is going to be rather less than the other two.

In knowledge generation we are focusing first on identifying the agenda, the priority research questions in our field, and second on synthesising the knowledge that already exists, pushing forward on systematic reviews.

And on evidence-to-policy work, it has become clearer and clearer to me that the evidence base for this type of work is quite limited. A few countries like Canada and the UK stand out as having good mechanisms and systems for getting evidence into the policy-making environment, but there has been very little experimentation with those kinds of mechanisms and systems in low- and middle-income country contexts. So it’s a little bit moving out into the unknown.

So in this area what we are trying to do is to focus on a handful of countries, and support them on implementing some of these mechanisms, and then to evaluate what seems to work and what doesn’t.

> **RHN:** These are mechanisms for getting research or knowledge into the policy environment?

**SB:** Absolutely.

> **RHN:** We are all learning about this as we go along, but what is your current view as to what look like the beginnings of good strategies?

**SB:** I think firstly that the evidence so far suggests that this kind of evidence-to-policy transfer is more likely to happen where the policy networks are quite rich – in the sense that these actors, researchers, civil society organizations, media and policy-makers do already interact quite frequently.

Much of the activity of WHO’s EVIPNet (the Evidence-Informed Policy Networks) has been trying to stimulate those kind of network, and I think that that is very important; but I also think that it’s likely to work better when you are doing it around specific policy issues.

So what we are trying to do at the Alliance is to work with policy-makers to identify priority policy issues that are coming up on their agenda within the next couple of years, and to then use that as a vehicle to build networks around.

For example we are commissioning policy briefs on specific issues that might reflect the systematic reviews available; to conduct ‘safe harbour fora’ or ‘deliberative fora’ where you bring all of those members of the policy network together under Chatham House type rules, with open dialogue but all off-the-record.

We’d like to open up a discussion between the researchers and the policy-makers, civil society organizations, and as far as possible the media, about what the research evidence is and how that relates to policy.

> **RHN:** Are your priority countries the same as EVIPNet’s?

**SB:** EVIPNet is working in a lot of different countries; we’re trying target our resources a bit more, and not just our financial ones but also our technical support.

So we are focusing on Vietnam, Kyrgyzstan, and the Regional East African Community Health (REACH) policy initiative countries – Kenya, Uganda and Tanzania [see page 23]. We are providing grants to all three of those initiatives.

Also, given our nature we are focusing more on health systems issues than EVIPNet, which is wider.

> **RHN:** And the issues that you are looking at in these countries – has the initiative come from them?

**SB:** In all cases. Yes. First the interest in looking at research-to-policy mechanisms has always come from the countries and typically has some degree of policy-maker buy-in.

But to be quite frank, I think that is one of the biggest struggles at this point – getting real policy-maker buy-in. Some policy-makers are already interested in research, but others – who may be more influential – are harder to get to the table.
This is one of the reasons we decided to focus on specific policy issues that we know will soon be on policy makers’ agendas. Because when they see how this can be instrumental to the work they are trying to do, then it will be easier to get them to the table.

> RHN: As for your policy briefs – will these be based on systematic reviews?

SB: To be honest I think it is a little bit undefined right now, for a number of reasons.

Firstly, if you look at the methodology of Cochrane-style reviews, which focus on the effects of different interventions, then in the health policy and systems research field there are relatively few evaluations of policies or interventions that give you enough data to do a really good systematic review.

So for example colleagues at the London School of Hygiene and Tropical Medicine have been working recently on a Gates’-funded review of different health financing mechanisms, but for things like social health insurance there are simply no studies that meet the type of standards typically used for Cochrane reviews.

> RHN: Is that so! And yet there are demonstration projects in social health insurance all over the place. But no-one has studied them properly?

SB: Well Cochrane identifies certain types of study design as being best suited to answer questions about effectiveness. For example a randomized controlled trial would be one of these; but how on earth could you do a randomized control trial of a social health insurance intervention?

So while some evidence can come from those kinds of studies, our sense is that often they are going to be insufficient for policy-maker needs.

After all, policy-makers are concerned not just about whether social health insurance works or not – they want to know how best to implement it. They need to know how to communicate it to the population, which part of the population to cover first, and so on.

So there are a lot of ‘how’ and process questions that policy-makers are typically interested in, that systematic reviews of effects don’t capture.

And once you begin to move away from that core, Cochrane-type of systematic review, the methodologies are much less well-developed and much more contested.

> RHN: Of course in this area of social and public health you are moving much closer to politics, aren’t you, which is where a lot of these policy-makers are sitting, and the political and cultural influences in countries become very important.

SB: Absolutely, yes. And that’s the other big question around these reviews – if contracting for health care services is shown to be effective in Mexico, Brazil and Argentina, what can we draw from that experience for Uganda, Tanzania and Rwanda, where conditions are very different?

So one of the real problems facing health systems research is how we generalise from a study in one country to another.

“ One of the real problems facing health systems research is how we generalise from a study in one country to another.”

SARA BENNETT

> RHN: Let me ask you about another broad issue. There is a tone that one hears in a lot of the literature and argument about the need for health research in driving health policy, that actually sounds more like ‘selling science’ than actually helping policy-makers. And I can imagine policy-makers looking at that from their political perspective and saying ‘this is just another interest group fac ing us’. So what evidence can we give them that research really is effective in helping them make complex policy decisions?

SB: [laughs] A very good question! I’m not sure that there is huge empirical evidence that supports that. You’ve got the recent series by Julio Frenk in The Lancet discussing the success of the evidence-informed policy process in Mexico; but you can’t have another Mexico facing the same policy issues and making decisions without any of the evidence that Mexico used! So it’s difficult to be clear about the difference that research made.

I think most people, if you put to them the question ‘would you prefer to have a policy that was informed by the evidence that was available, or a policy that was un-informed?’, would typically go for the policy informed by evidence.

It’s more a question firstly of the nature of the evidence that’s available; then whether it’s in a format that can be accessed easily; and then whether the knowledge base really exists in a form that would be useful to making a policy decision.

Also I think it’s a matter of recognizing that evidence is just one among many factors that are going to influence policy, and being up-front about that. We need to admit that that’s absolutely fine – that sometimes values or political circumstances will outweigh what the evidence has to say, but let’s at least be clear and open about the evidence to the extent that we can.

Continued on page 22
extend the integrated management of childhood illness (IMCI), for example. Or governments have also experimented with schemes that have tried to get people to do placements in rural areas once they’ve finished school; those don’t seem to be so successful. Recruiting people from rural areas, going out of your way to give preference to candidates who’ve been brought up in remote areas – that seems to be something that looks like it might work to some degree. But the evidence on the effectiveness of all these different strategies is pretty weak.

SB: We were involved in preparing some of the evidence for that meeting, but I would share some of the criticisms. One of the challenges at Khon Kaen was that there weren’t clear policy questions driving the agenda. There was a lack of focus.

There had been a series of e-mail consultations with EVIPNet groups in different countries, asking what policy-makers would like discussed at Khon Kaen, but the results had been complete topics like ‘maternal and child health’. But that’s not a policy question, it’s a whole set of issues.

And one of the things that came out of Khon Kaen, I thought quite clearly, was that that kind of discussion forum would be much much more effective at country level: they wanted country dialogues. I think then you could make it much more specific, so it’s not just about ‘maternal and child health’ but, say, ‘how to extend the integrated management of childhood illness (IMCI)’, for example. Or closer to the areas I know, ‘how do you retain health workers in rural areas?’ – something much more specific. There are actually some good reviews done around the latter question and I think policy-makers would find it interesting to see how different countries have addressed that.

RHN: Has the Alliance made any attempt to any create such nodes, for policy briefs or systematic reviews, for example?

SB: That might be part of it, but whether that’s the most cost effective answer, I don’t know.

Governments have also experimented with schemes that have tried to get people to do placements in rural areas once they’ve finished school; those don’t seem to be so successful. Recruiting people from rural areas, going out of your way to give preference to candidates who’ve been brought up in remote areas – that seems to be something that looks like it might work to some degree. But the evidence on the effectiveness of all these different strategies is pretty weak.

RHN: To conclude, let’s talk about the future of the Alliance. How do you see it developing? What’s your strategic plan?

SB: There’s a couple of core issues. I continue to think that health policy and systems research, both the generation of that and its application to decision-making, continue to be very neglected. So I think that the Alliance has an important role to play in raising the profile of the field, attracting additional funding to the field, and underlining the importance of what can be done if evidence is better applied.

The second part of it is that health policy and systems research, more than any other type of research, is context specific, as we’ve discussed – and I think that for the Alliance to be successful in the long run, i.e. over the next ten years, we need to be looking and thinking at how we develop hubs or nodes out in developing countries. I don’t think that the Alliance could ever grow by being a large centralised research programme.

We need to get the field of health policy and systems research to grow through networks and nodes in different regions so we can be much more context specific.

RHN: Briefly, isn’t the answer to that to make sure they have schooling for their children, pay them well and pay them regularly?

SB: That might be part of it, but whether that’s the most cost effective answer, I don’t know.

Governments have also experimented with schemes that have tried to get people to do placements in rural areas once they’ve finished school; those don’t seem to be so successful. Recruiting people from rural areas, going out of your way to give preference to candidates who’ve been brought up in remote areas – that seems to be something that looks like it might work to some degree. But the evidence on the effectiveness of all these different strategies is pretty weak.

RHN: It is striking, from the figures on the Alliance website, how little is being spent on health systems research in countries, down to 0.01% of health budget in some cases....

SB: Yes, and yet there are commitments for five per cent of external support for health programmes to go into research. Donors are putting a lot of money into health systems, if you look at GAVI, the Global Fund, DFID – large amounts of money are flowing to health systems programmes – but very little serious evaluation is being done.

RHN: And why is that, would you say?

SB: It’s politically a little complicated. As programmes like the Global Fund and GAVI have tried to roll out and scale up, they’ve run into health systems constraints at every turn – so now they are beginning to look at those. But at the same time it’s a little bit awkward to acknowledge how flimsy is the evidence base that you are working from, as that undermines what you are trying to do.

One of the phrases that were used at IDEAHealth was that you have to ‘mend your boat while you sail it’. I think that’s the case with health systems research. We can’t stop people using specific innovative mechanisms such as contracting by saying ‘it hasn’t been proven’. We need to use these new and innovative ways of strengthening health systems and at the same time evaluate them seriously. RW
> Research to policy

Reaching out to policy-makers

The growing East African health organization REACH is making efforts to link research with policy-making.

COMMUNICATION BETWEEN RESEARCHERS, POLICY-MAKERS AND THE PEOPLE COULD IMPROVE IN EAST AFRICA, IF REACH HAS ITS WAY. CIRCUMCISION TO REDUCE HIV TRANSMISSION AND MATERNAL MORTALITY ARE TO BE TACKLED FIRST. BUT GROWTH SINCE ITS INCEPTION IN THE TANZANIAN ESSENTIAL HEALTH INTERVENTIONS PROJECT HAS BEEN SLOW, AND BUDGETS REMAIN MORE DREAMS THAN REALITY.

by Esther Nakkazi

KAMPALA, UGANDA - Male circumcision is becoming a proven new prevention technology that substantially lowers the risk of contracting HIV. The research findings were released last year after successful research in Uganda, Kenya and South Africa.

Such research could have a powerful impact of reducing HIV/AIDS infection among the people of East Africa – but only if the right policies were implemented, among them a policy option of offering free or subsidized circumcision to all males aged 15-49 years.

But is it as simple as that? For instance in some communities in East Africa a newly circumcised man is expected to have his first sexual act with a woman outside his home. Promoting circumcision would thus be counterproductive in such a community.

So more research would have to be done on this policy to guide the actions to be implemented – research in areas like the desirable training for health workers, facilities and equipment required in health centres for mass circumcision and most importantly the type of education needed to dispel the perception that male circumcision provides complete protection against HIV.

REACH will act as an intermediary in the use of research results for policy. It will put the region’s researchers and policy makers on the same platform, to discuss the best actions for better health, Nelson Sewankambo, Dean of the Medical School, Makerere University and a front runner in the REACH project, told Real-HealthNews.

The first topic, male circumcision, was chosen because HIV is a topic of common concern to all three countries in the region – Uganda, Kenya and Tanzania – he said. The data generated was from research from Africa and involved two East African countries.

“We shall pick it up and go through the whole process, synthesize, summarize it and package it for policy makers, giving them options for policy and see if these would be translated into actions that improve health. A researcher has already been identified for this,” said Sewankambo.

Another persistent problem, maternal mortality, will need deep research to get to the core reasons of why it is so persistent.

“I have requested a review of the whole subject. We shall have an open meeting to discuss it with all stakeholders, and the country nodes will plan deep research,” said Gabriel Upanda, the Executive Director of REACH. “Some research has been done but it is not sufficient.”

Currently REACH is establishing a regional hub to be based in Arusha, Tanzania, with country nodes in Uganda, Kenya and Tanzania. The East African Community (EAC) has given the project office

Continued on page 24
space in Arusha, and the office should be running by June 2007 says Upanda.

“We have identified research centres in each country that will feed into the nodes. The country nodes will do research and policy analysis,” said Upanda.

Although funding remains one of the most pressing challenges of the project, Canada’s International Development Research Centre (IDRC), the African Development Bank (ADB) and USAID have provided seed funding, he says.

For the initial five years the budget for REACH is projected to be US$ 10 million, beginning at US$ 1.8 million for the first year. At least 50% of this is to be sought from the donor community. The Swiss Tropical Institute in Switzerland is ‘talking’ with REACH to provide more funds, and more donors are expected to come on board.

Member countries are also expected to contribute 2% of the annual budget every year. However for this financial year [2007] no member country has met its financial obligation. “We hope next year, countries will make their annual contributions since they have already agreed in principle and sector ministries endorsed it”, said Sewankambo. This year it was impossible because their budgets had already been allocated, he said.

According to Upanda, 15% of the budget will go into direct costs of the East African Health Research Commission – a revival of the East African Medical Research Council, a centre of great repute and excellence under the original East African Community (EAC), which collapsed in 1977. The Council was in close cooperation with the EAC partner states in health policy, research, and promotion of the exchange of research findings in the region.

The Commission was renamed and re-established after the revival of EAC in 1999. REACH will be the research wing of the Commission handling policy, research and practice.

Under REACH two types of meetings – open and ‘safe harbour’ meetings – will be held. In the latter a few key people will be identified and invited to go into deep-er issues that interest individual countries, without reporting, while in the former all stakeholders will be invited to discuss and identify priority areas for research and policy openly.

REACH also aims to help researchers get their work published. “Most researchers would like to present their findings to international and local publications, so we shall facilitate that,” said Upanda.

Research communications should also be improved, as the project aims to take research papers, synthesize them and put them in simple language and communicate them to the appropriate level.

“There is an urgent need to get results to the public quickly, and improve REACH’s communication with the communities who have a right to the data and can benefit from it,” said Upanda.

“We will strengthen the capacity at regional and country level in knowledge translation, so research is utilized by the communities and the decision makers,” he said. ‘Peer review papers’, where scientists will report to other scientists, will be another activity.

REACH was originally conceived in 2001 in Tanzania, after a successful project, the Tanzania Essential Health Interventions Project between the Ministry of Health and Canada’s IDRC. TEHIP was established to test innovations in planning, priority setting, and resource allocation at the district level – and to make use of the results.

During TEHIP’s operation in the two districts of Rufiji and Morogoro, a lot of data was generated, collected and disseminated to the rest of the country. This data was also communicated to Kenya and Uganda to be adapted to solutions for local needs.

When EAC was revived, with its harmonization of the policies and operations in the three countries, Tanzania sold the REACH concept to the other states. “The idea was accepted in principle and consultations started in Uganda. We found that there was a lot in common and the needs were similar so the idea was adopted,” said Upanda.

Even if REACH has not achieved much yet, there are big plans. It has been described as ‘starting small but thinking big’. Its unique concept and set up has influenced many countries and caught the eye of WHO, REACH claims. WHO’s Evidence for Policy Network (EVIPNet) is using similar ideas to REACH, and is now working with seven countries in Africa, seven in Asia, and will soon include ten countries in Latin America, EVIPNet director Ulysses Panisset told RealHealthNews.

Meetings and collaboration between EVIPNet Asia and Africa with REACH have already begun, the last being in Bangkok, Thailand in December last year.

REACH is also poised to grow, built on the EAC regional economic grouping. Rwanda and Burundi have joined EAC, and will thus be a part of REACH. The challenge is exactly how they will be brought on board.

Things done for the first time always pose challenges. There is no experience to build on and there is continuous discovery as the project is implemented. Getting agreement between all parties in a regional project is a challenge. But now the concept has been implemented, REACH has to ensure that the system works – excellence is paramount, says Sewankambo.

“We need to build credibility and a track record. This means doing real work to the highest standards. REACH should become a household name and countries should buy more into it for sustainability,” he said.
Safe motherhood

Dying mothers: from the evidence to political will

Mothers die overwhelmingly because they are poor – but this gives an opportunity for targeted action.

The end of the first phase of the IMMPACT global research study on maternal mortality leads to one main conclusion – that in any community, rich or poor, the poorest women suffer by far the worst maternal mortality. So to reach the Millennium Development Goals, the poor should be cared for first – and the message must be clearly communicated to policy-makers. Director of the IMMPACT study Wendy Graham explains her conclusions.

The number of mothers who die at or around childbirth is remarkably difficult to measure, but according to estimates made by WHO, the UN Population Fund (UNFPA) and UNICEF in the year 2000, the annual global figure was 529,000 lost lives. These deaths were almost equally divided between Africa (251,000) and Asia (253,000), with about 4% (22,000) occurring in Latin America and the Caribbean, and less than 1% (2,500) in the more developed regions of the world.

The global figure is estimated to be 400 mothers dying for each 100,000 live births – a figure called the ‘maternal mortality ratio’ (MMR). By region, the MMR was highest in Africa (830), followed by Asia (330), Oceania (240), Latin America and the Caribbean (190), and lowest in the developed countries (20).

Millennium Development Goal Five calls for the maternal mortality ratio to be reduced by three-quarters by 2015.

The IMMPACT research study on strategies to reduce maternal mortality in developing countries was launched on 1 June 2001 with initial development support from the Bill and Melinda Gates Foundation, the United Nations Population Fund (UNFPA) and WHO. Since then other donors entered the list, including the UK’s Department for International Development (DFID) and the United States Agency for International Development (USAID).

IMMPACT began its first full four years of operation in February 2002. Results of that phase of the research are now in, and were reported at a dedicated Symposium in London in February 2007. Wendy Graham, the Director of the IMMPACT, speaks here to RealHealthNews about the results, and what she believes must happen next. In later pages we carry a story on maternal mortality in Uganda, and an interview with the Minister of Health for Sierra Leone, Abator Thomas, who attended the IMMPACT Symposium.

RhN: After all your work, what are the main conclusions from IMMPACT?

WENDY GRAHAM: Since the Symposium in February, I’ve been trying to distil and distil. I think for a high-level decision-maker I’d say there were three main messages:

The first conclusion is that the burden of maternal mortality is always much greater amongst the poorest women.

The second is that because of where that burden lies, this gives countries an opportunity to accelerate progress to Millennium
Development Goal Five [a 75% reduction in maternal mortality by 2015] by prioritizing quality skilled attendance at delivery for the poorest women.

And the third message is that monitoring progress to Millennium Development Goal Five is possible, particularly using tools from IMMPACT.

> **RHN:** Wasn’t the poverty correlation pretty predictable?

**WG:** Well it sounds like common sense; but my answer to that is first, why are we thinking that there will be something new, when this study affirms what we knew; and second, we’ve helped by quantifying that effect.

For example in Indonesia there is a six-fold difference between rich and poor in the uptake of skilled attendance at birth – and a four-fold difference between rich and poor in the risk of maternal mortality.

So now we can put numbers on it, and by doing that we can also show where you can start to have an effect. Unless you give the poorest access to skilled care at a price that they can afford, you can’t affect maternal mortality.

> **RHN:** To what extent, would you say, can research on maternal mortality make a difference?

**WG:** I could throw that back to you – because the frontier is not lack of evidence, the frontier is communicating the evidence.

When we launched IMMPACT, it seemed at that time that the bottleneck was evidence on strategies. And we and others, like the Averting Maternal Death and Disability programme (AMDD) and Family Care International (FCI), have helped to fill that gap.

For strategies we could never have grade one, randomized control evidence, because there are too many technical challenges to doing those real-world evaluations. Nevertheless there is now a better understanding from us, and from others, of packages of care that can make a difference. The issue now is the political will to act on that evidence. I think sometimes evidence is even used as a bit of a cop out. We don’t have evidence of the kind you can get for specific clinical interventions for children like vitamin A, but we all know that there is no magic bullet for maternal mortality.

So I think the goalposts have moved – there is nothing really new to say: it’s health system strengthening, it’s a multi-pronged approach, with effectively reaching the poor being the only way that you’ll have an effect on maternal mortality by 2015. The frontier now is the willingness to do that.

> **RHN:** Is the immense gender inequality that exists in many countries going to be an obstacle to political commitment?

**WG:** It is in some ways, but in Africa for example there’s a growing number of very strong women activists; and I think there is a role for some of these civil society groups.

One of the criticisms of the safe motherhood movement is that we talk to ourselves all the time, and we don’t talk to others enough about the issues. Women’s groups and civil society groups are a case in point – I think that in terms of making the case for women’s rights to life our issue has become rather medicalised. Other groups outside the health movement are much stronger.

So yes, there is a gender element, but I am more optimistic about that in Africa than I am in Asia, India and Bangladesh in particular. This is partly because there are many economically strong women in Africa – although there are pockets in for example Ethiopia and Sudan and Northern Nigeria that are not so strong. But in general in Africa women have access to the means of production.

> **RHN:** Nevertheless if there is some stronger evidence that can be brought to a decision maker, it can make a difference, can’t it? For example Anne Phoya of the Ministry of Health in Malawi said at the IMMPACT Symposium that the importance of strong evidence is that “it helps you negotiate with the treasury”.

**WG:** Yes, and that’s where the translation of research to policy-making enters: the two need to come together smoothly rather than collide. Because ‘what works?’ is never going to have a simple answer, not the simple answer that a politician would want.

The closest I’ve got to that is ‘focus on the poor’. Then there’s the way to say that – I could say that they can’t reach the 2015 target without focusing on the poor; but that’s rather negative, and I think the best way is to say that they can accelerate progress that way.

But at the same time we have to be careful about not making it sound overly simple. Focussing on the poor is not straightforward.
Another thing that struck me forcibly at the Symposium was how many factors can be said to cause maternal mortality. There is a wide spread of different issues that you have to address, isn’t there?

WG: There is. And that has bedevilled the history of safe motherhood. Early in the history of the movement we were talking about training of traditional birth attendants, or antenatal care and screening for example – very specific things as if they might be the solution. Then in the early 1990s it got broadened to become part of the reproductive health agenda; and then it got on board with health system strengthening, which of course is genuinely what needs to happen.

But the history of safe motherhood is that it has got broader and broader over time – and clearly with gender issues coming in, including the gender Millennium Development Goal [MDG 3, to promote gender equality and empower women], it’s become very very big.

Which it is; but from a messaging point of view people don’t want to hear ‘it requires strengthening of the whole health system’, or even ‘it needs poverty reduction’. And that’s the problem. So I think it’s an art, so the scientists who are generating the evidence can feel comfortable and not uneasy or untruthful.

Research also reveals uncertainty – but that’s also unpopular among decision-makers! So after the Symposium I was faced with two groups of people, one saying ‘I wish you hadn’t mentioned uncertainty’, and the other ‘I wish you’d said more about that’!

Disagreement among scientists is also a problem, isn’t it – and I understand that there has been a bit of a division in the maternal mortality community between those who believe that the solution is to provide quality care at a first referral health centre, and those who believe it’s best to provide it in the home...

WG: Yes – partly, what you are picking up there is a balance between what is right for the mother and what is right for the child. It’s very difficult, and in communicating on this you can sound as if you are not for child survival, whereas everyone working in maternal health is also very much wanting to see improved child survival, and vice versa; so it’s not as if we don’t have the same ultimate goals.

But if you are put on the spot, and you are asked simply how to prevent women dying, we know that home-based care simply can’t have that dramatic effect – because sooner or later you are going to need emergency obstetric care, a blood transfusion, or life-saving surgery.

That’s not to say that you can’t do some things at home; but if you are saying what is the route to avoiding mothers’ deaths, we don’t have the same sort of home-based care that might work for a child like oral rehydration salts (ORS) for diarrhoea.

"Effectively reaching the poor is the only way that you’ll have an effect on maternal mortality by 2015. The frontier now is the willingness to do that."

WENDY GRAHAM

I think it’s clear that maternal mortality is a wonderful test case of whether a country is genuinely committed to improving its health system, or at least a portion of that system, because so many health interventions for the poorest remain vertical, focused on very particular interventions, which they drive through; and they don’t link up with one another. Here, it seems to me, you have to link up a series of different ideas.

WG: Absolutely. Because even if there were a magic bullet, you’d need an implementation mechanism to deliver that. Take antiretrovirals for HIV/AIDS for example. I know South Africa quite well, and the thing that is creaking at the seams is the delivery mechanism – the health system.

Although some areas of disease and health give the impression that they can work without the health system, they meet it sooner or later. Unless you have a project that has so much money that it can create its own health workers and its own drug supply system and so on, sooner or later it has to fall back on the health system.

Some groups have addressed that problem of the health system more than others, and the maternal mortality group has just had to address it, because what you need to reduce maternal mortality is a functioning health system.

To what extent has IMMPACT been able to harden up the numbers on maternal mortality?

WG: I think we’ve made a significant contribution in measuring the variation within countries. In many countries, even quite small countries like Sri Lanka, national figures hide more than they reveal. And the challenge has always been to measure at a subnational level – though some countries don’t even have a national figure.

So we’ve had to develop monitoring methods and evaluation instruments that can pick up whether there has been an increase in skilled attendance and so on locally.

So what’s the story in Sri Lanka?

WG: We didn’t study Sri Lanka directly. But we know that although the national level of skilled attendance is very high, in some parts of the country it falls below 50%. So using our evidence on the correlation between skilled attendance and mortality, one can predict about a two-fold higher mortality in those areas. I don’t want to diminish the work of Sri Lanka – it is a success story – but all over the world there are disadvantaged groups that don’t benefit in the same way.

Tell me about the IMMPACT ‘tool kit’, which was presented at the Symposium. Because it seems to me that one of the most important conclusions, or products, of IMMPACT, has been a way...
to measure this kind of variability within countries. Have you got something here that is practical for a small team to work with?

WG: Well they vary in terms of practicality. In our toolkit, on our CD package, we purposely selected tools that we thought others outside of research could use.

But we also have developed some intensive research tools – so we have a mixture. Some can be picked up and used by a district outside a research context, and others that because of their resource requirements in both funds and skills, will always remain research tools.

RHN: Can you draw that distinction for me a bit more sharply? What's the difference between relevant data collection within the health system, and research – how do you distinguish the two things? What's the research going to be doing that the data collection is not doing?

WG: It's in terms of the volume of information, and contexts. For these evaluations we were carrying out, we were working outside of a trial design, looking at existing strategies. So we had to look very carefully at contextual factors, to see if there was something else that was changing that could easily explain the improvements we saw – these would be confounding factors.

When you come in as an external evaluator that's right, and you must measure everything that moves – because you don't know for example whether roads are suddenly going to be finished and change referral mechanisms much more than safe motherhood has ever done! So it becomes a 'measurement fest' – which is excusable and defensible for a very specific question.

But routinely, you would not need to gather that volume of information. On the other hand, it would depend on what decisions you wanted to make – is it an early warning system to know whether a particular hospital is failing to deliver, or more complex?

In tools, the bottom line is almost the other way around: you choose the tool depending on the decision you are trying to make. Because with some types of information, for advocacy for example, you don't want ropey data – but it's not the same as asking whether to commit a major resource to a new drug, for example.

RHN: You used the phrase 'the bottom line'. Won't the bottom line to the minister be how many lives can I save at what cost – and cynically, how many do I save in my political domain?

WG: Absolutely, and we have instruments now that can either measure it directly or can estimate.

RHN: Regarding the political credibility of evidence, Sam Adjei of Ghana Health services made some interesting points at the Symposium. He said the institution creating the evidence has to be credible, and politically neutral. Well that's generally true of an academic body. But then he stressed that there needs to be 'ownership' – which often means there has to be a local research group involved, with good connections with the Ministry so the ministry itself knows about and wants the research from the beginning...

WG: I think we've learned quite a lot of lessons on that!

RHN: Well do tell us something about that.

WG: When I look at the timeline and where we are, I think some of our early processes were very slow. But then when I look back I realise that we were creating this 'pull' for the evidence, and that's not something you can achieve overnight. It means working through and with, as you said, credible local institutions that have the ear of the users of the information, while keeping a degree of impartiality – so that you can tell both good news and bad news with impunity.

Interestingly that was very straightforward in Burkina Faso, but it was much harder to achieve in Indonesia, for a variety of reasons. So I think 'neutrality' never really exists in some situations, because the research institutions are so much a part of the government that they can never be neutral. So we have to acknowledge that as well.

It can be quite hard for a research institution to say in those situations that there has been no obvious progress. You can say this in a variety of positive ways, but it can become quite hard – and we can underestimate the difficulty that puts research institutions in.

RHN: What do you think actually could be achieved by applying your recommendations?

WG: Well I think that by 2015, by effectively focussing on the poorest with quality skilled attendance at delivery, countries will make detectable improvement towards Millennium Development Goal Five.

But it must not be poor care for the poor – that's the risk. By talking about targeting and skilled attendance specifically for the poor my worry would be that this is seen as a second-class service, and it shouldn't be. There should be skilled attendance, and it should be specifically given first to the poor.

Some countries have had 20-50% declines in mortality over times equal to the period we have left [to 2015], but it's a lot of effort, and there will be questions of sustainability.

A 75% reduction in mortality, the MDG itself, is however a monumental goal.

There are two schools of thought there – one that it was never really meant to be taken that only 75% really mattered, that it was a lever to help stimulate countries; and the other, in the MDG community, that there is going to be huge disappointment if we don't reach the goal.

RW
Sierra Leone wants science to save mothers

Abator Thomas, Minister of Health for Sierra Leone, explains why she seeks evidence for her policy-making.

Mothers are dying at the rate of three jumbo planeloads each day, at or near the birth of their children. Most are dying in Asia and in Africa – which brought the Minister of Health for Sierra Leone to London recently to hear the conclusions of a global study on the issue, the IMMPACT research initiative [see page 25].

RHN: So you don’t believe in what the economist John Maynard Keynes is reported to have said, that “there is nothing a government hates more that to be well-informed: for it makes the process of arriving at decisions much more complicated and difficult”!

AT: I don’t really think so! If you want to be objective, then look at the evidence, and see how it relates to your country and what you are doing.

RHN: IMMPACT has stressed the importance of the ownership of research, by the country where the research is being done, and they are keen to work with local researchers. But so far, I don’t think IMMPACT has worked in Sierra Leone. Do you think local ownership is a good idea?

AT: Of course it is! I think whatever research is done, there should be local ownership – that makes it more authentic. You can take hold of it and use it in a very productive way – and even encourage other people to use the results of the research.

RHN: Ownership also means that you are enabled to ask the researchers some questions, that maybe they hadn’t thought of, that are relevant to your problems.

AT: Exactly – in fact a session I was at a few minutes ago brought out just that. They were looking at the gender perspectives of the problems women were having in getting access to health facilities to deliver their babies. And someone asked simply: “Have you ever talked to the men? It would be a good idea to learn their own perspective – to see why some things are easy but others are hard.” That was a good question.

RHN: Uche Amazigo, the Director of the African Programme for Onchocerciasis Control (APOC), told RealHealthNews last year that she believed strongly in the need for more women health researchers in Africa, to ensure the right questions are asked – particularly of women. Do agree with that?

AT: I quite agree with her, because when a woman interviews another woman, she brings out certain things that a man would not think of. You have your basic question that you are trying to ask, but especially in qualitative research these questions lead to something else – and you need the insight to know where lead that interview to get deeper answers.

RHN: Particularly on issues of gender bias and women’s concerns about men – she wouldn’t want to express herself as openly as she might to another woman.

AT: That is quite true – often women feel that men come with preconceived ideas, and they try to lead you away from what you want to say sometimes! But with another woman you know there is that empathy. You know that she understands what you are saying – you don’t have to explain it too much! You don’t have to ‘wash the person’s face’ to see if he understands what you are saying. You feel you are talking to a kindred spirit. So you are not ashamed of admitting certain things, as you are sure she would understand.

RHN: Are there many women health researchers in Sierra Leone?

AT: No, not many at all. Just a handful. But in Sierra Leone we are really pushing the gender perspective of things, so a

Continued on page 30
My administrative skills!... What are your goals? Sierra Leone, as Minister of Health?

Yes that might be one of the reasons, but I think another might be for my administrative skills!...

I’m sorry, I didn’t mean to diminish those!

Yes, that might be one of the reasons, but I think another might be for my administrative skills!...

In what sense?

[laughing] because the caregiver will be a woman if the man is sick, whether it’s his wife, or mother, or sister. And when you lose a mother in the family, the husband suffers, as well as the children. So I think health has a very big gender component, and it is very right for us to look at it from that point of view.

so what is your programme in Sierra Leone, as Minister of Health? What are your goals?

Well my main priority at the moment is to reduce infant and maternal mortality. Some of the ways we can do it are in the harmonization of efforts. As you are aware, Sierra Leone is right at the bottom of the Human Development Index. So we have a lot of NGOs and donors and others working on these issues. But because everyone is doing their own thing, coming in and working where they want to work, I don’t think we are having the desired impact.

So one of the things we are pushing is to come up with a harmonized approach, with a “roadmap” so we see where we want to go, how we want to get there and when we want to get there.

“We have a lot of NGOs and donors and others working on these issues. But because everyone is doing their own thing, coming in and working where they want to work, I don’t think we are having the desired impact.”

ABATOR THOMAS

What part does research and evidence play in these goals? Can you immediately apply techniques that you can glean from international reports, or do you need to do some local investigations about what works in your country?

It’s a little bit of both, but more to do with local investigations. It’s good to do local research to see what people think, what they are doing and why; and in fact, when you have local investigations I think that’s the beginning of sensitization – because you talk to people about what you want to do and why. So when the project starts, it doesn’t come as a bolt from the blue. Especially when you have community participation with focus groups, with the beneficiaries participating in the research.

What are the particular challenges you face in addressing maternal mortality and infant mortality in Sierra Leone?

Well there are two main issues. The first is the funding – because to reduce these things you have to have funding. For example at this meeting we were talking about free delivery – someone has to pay for that. And the second is human resources. You have to have the human resources, no matter what policies you come out with, no matter what strategies you have. If you don’t have the human resources to implement them it becomes very difficult.

Both of these are big problems in Sierra Leone. We are just beginning to get some assistance with financial resources from UK’s DFID and the World Bank; but we really need to work at our human resources. Even before the war, we started having a brain drain, but it accelerated during and after the war.

So we have to find ways and means to either bring some of these people back, or to train a lot of people very quickly. We are looking at how to train midwives very quickly, and at how we might be able to get some non-specialists to perform specialist tasks. We are looking at the whole gamut.

That’s why I find this IMMPACT Symposium very interesting, because it has given me a wide range of things that I could take back and encourage our people to do; either through bringing IMMPACT to Sierra Leone or seeing how we could use some of their information to get the results we need.

I understand that it’s been rather unfortunate in the field of maternal mortality over the last few years that there has been conflict between different camps over how mothers might be saved, between those focused on home-based care on the one side, and those focused on improving access to and maternal care at first referral health facilities on the other: two models of care. Where do you stand on this, or how will you reach a position on this?

Well again by the evidence we have in our own country.

Do you have enough health researchers to get that evidence?

Yes I think so, with some assistance from outside, people who have done it before. I was talking here to one of the researchers from Ghana, for exami-
ple, and we were thinking it would be a good idea for him to come over and help us set up some of the research programmes we need.

>RHN: This research should obviously be not simply academic, but closely integrated with the political and planning process, shouldn’t it?

AT: Yes of course. And also it should be action research, so that people who will be involved in the implementation stage are involved in the planning and research.

>RHN: Do you have researchers who are keen to pursue this kind of investigation?

AT: Yes certainly, because we have a medical school and a lot of people working in public health. So it would be easy for them to come up with the answers – that’s why I said ‘action-oriented’ research, because they are working in situ, and will be able to carry out the research very effectively.

>RHN: Do you have targets on infant mortality and maternal mortality?

AT: Well we are trying to work as far as possible with the Millennium Development Goals, to get as close to the targets as possible.

>RHN: What is the vaccination rate in Sierra Leone?

AT: It’s 70%. It has increased quite a lot recently, especially when we do campaigns. The routine vaccination levels are not so good but we are seeing how we could improve on that.

>RHN: Where and in what communities do the greatest challenges remain?

AT: In the harder to reach areas, the isolated communities, the smaller communities. You know Sierra Leone is quite riverine, so sometimes it’s very difficult to get to some communities. And in some areas the communities move, for example from villages to farms. But when we have campaigns we target them specifically.

>RHN: And the big cities?

AT: The big cities are not so difficult, though some of the population is very mobile, coming to town to trade – it’s difficult to find them in their homes! But we are also going to the market places, where you get a lot of women and children. So you have to use different strategies for different communities.

>RHN: One last question about the communications between the health research world, nationally and internationally, and policy-makers. How good is that, and what could be done to improve it, do you think? Researchers are being encouraged in the UK to communicate their results to policy-makers, but I suspect that it’s best if this is becomes two-way process. What’s your view?

AT: Well I think as you say, that it should not be a one-way process from research to policy. I think sometimes the policymakers should be given the opportunity to decide what research he or she wants done, to benefit his or her own community. Rather than people doing the research and saying “this is the evidence, why don’t you adopt it”.

> by Esther Nakkazi

Victo Nabuule is a midwife at the obstetrics and gynaecology emergency annex ward in Mulago Referral Hospital. So far this Saturday morning she has registered six patients.

Women enter the ward in threes to sit on the bench in front of her table for Continued on page 32
registration. Outside the ward is a very long queue. The ward handles emergency cases for pregnancies below 28 weeks; above that the women go to the labour ward.

Some are in so much pain. They tell her their names through clenched teeth; others hold their fists tight wriggling on the bench. Victo Nabuule occasionally raises her voice to get the particulars right. On average she registers 20-30 women a day at the ward on fifth floor.

In the ward, the doctor is doing his morning round with two other nurses. One of the patients in the ward is on a blood drip. She shouts out but nobody pays attention; her voice is weak and faint.

She tries to sound louder this time, “nurse I can not breathe I am in so much pain”. Midwife Nabuule consults her registration book. The patient is called Lydia Nambuya, 34 years old. This is her fourth pregnancy and she was brought in last night screaming with pain.

Lydia Nambuya and midwife Victo Nabuule.

She probably never would have come to hospital at all – but her husband came home drunk last night and kicked her hard on the stomach. The immediate solution the hospital offered was blood, because she was very anaemic.

“She is trying to get our attention, let her wait for her turn”, says Nabuule. “The doctor will get to her bed soon”. The midwife is not being mean; women here have to endure pain during pregnancy and during childbirth.

The woman screams again. “Doctor please help me, the pain is killing me.” But he goes on with his work. At least she gets a nurse’s attention. “You say you cannot breathe but you can talk! Can’t you just be patient and wait for the doctor to reach your bed?”

Ironically this is one of the reasons that so many women die. They wait for too long to come for medical attention; in most cases their conditions have gone beyond control and have become fatal.

On average sixteen women die of pregnancy-related problems everyday in Uganda, says Olive Sentumbwe-Mugisa, a professional officer for Family Health and Population at the World Health Organization (WHO).

Traditionally women go to a plantation, hold on to a banana plantain and push the baby. Banana leaves are spread below to act as a bed for the delivery and the TBA stands by, to administer herbs. But sometimes they can only do so much.

In case of serious cases like obstructed labour and ruptured uteruses mothers are rushed to hospitals – if they can get there in time.

“They usually bring them here covered in mud and some of them die. Even when there is a health centre near the home, some are rushed to Mulago Hospital because almost everything here is free and sometimes available”, said midwife Nabuule. “We had a woman who lives about 24 kms from Mulago who had a ruptured uterus. She is lucky to be alive. Most of them die.”

The government has built new health centres in all the districts in Uganda. The 2005/6 health policy statement says 400 ‘health centre IIs’ were constructed bringing the total to 1593 facilities. Another 180 health centres were renovated and 169 more advanced ‘health centre IVs’ have been set up complete with maternity wards, operating theatres, staff housing and equipment. These were introduced to bring lifesaving skills nearer to the population.

The result was that 72% of the population were brought within five kilometres of a health facility, says the government. However, the centres have not had much impact on health so far because they are inadequately manned and equipped. Doctors shun them, and so do patients.

If they were properly staffed and equipped they could attend to emergency obstetric complications, which happen especially at delivery time, and over the next 42 hours after birth. Two thirds of maternal deaths are said to take place around this time.

“It is useless to build health centres that are not well equipped. The doctors’ main problem might not primarily be how much they are remunerated, but there need to be satisfactory working conditions to enable him perform his duties,” said Nelson Sewankambo, chairman
of Uganda Chartered Healthnet. (UCH is a non-profit NGO, which promotes the use of information and communication technologies by health workers.)

In practice, most of the health centres are just buildings with no nurses, doctors, or laboratory equipment – and the operating theatres are not supplied with blood. Therefore they cannot handle obstetric emergencies.

Blood is essential – because excessive bleeding in pregnancy-related complications in Uganda accounts for about 26% of women who die in childbirth.

The Uganda Blood Transfusion Services (UBTS), a government body charged with providing free and safe blood for transfusion in health centres, usually fails to collect enough blood.

UBTS collects around 120 000 units of blood a year. The scaling up of the health centres has created a 45% increase in demand – but not much more blood is collected. Some 95% of the blood is collected from voluntary, non-remunerated donors, most of them school children.

In Uganda more than 50% of blood collected is required to save lives of severely anaemic children, and a further 25% for transfusion of women with complications of childbirth. The rest is for accidents and other conditions.

But UBTS has a 50% funding shortfall already – after the European Union (EU) stopped funding in 2005 and the US Presidential Emergency Plan For Aids Relief (PEPFAR) cut its budget to the bank by half last year.

EU funding for the Uganda safe blood project including the Blood Bank started in 1990. Fifteen years later it has closed its doors.

“For quite sometime we have had a funding deficit which has affected especially our infrastructure development. Our laboratory at Nakasero was built to handle 20 000 units of blood, but because of increased demand they are handling more than twice the amount – about 50 000 units per year. Other regional blood banks are in Gulu, Mbale, Mbarara and Fort Portal.

Uganda has a national policy on blood transfusion. The health centres remain undersupplied, but UBTS is supplying almost all the hospitals in Uganda – over 90 of them – with almost all the blood they need: safe, screened blood that is free of the HIV virus and hepatitis.

But excessive bleeding is just one of the reasons for maternal mortality. At least 22% of women die due to infections developed during pregnancy, labour, birth and even after birth.

Dr Sentumbwe-Mugisa says the women develop severe infection and die because the birth canal, the abdomen, or sometimes the blood becomes infected, a condition called septicaemia. Other women get infection after abortions.

“There is no reason that a pregnancy should kill a woman. This is a common problem in the region which has persisted in spite of available information on how it can be reduced, said Sewankambo.

The Regional East African Community Health (REACH) project that attempts to link research and policy has maternal mortality high on its agenda [see page 23].

Sewankambo said there are many health system problems. Some studies have noted that many women attend ante-natal clinic, but the majority do not come back to the health centres for delivery.

It might be blamed on the attitudes of health workers, substandard care given to the pregnant women, or lack of transport to the health centres. But Sewankambo argues that even when the health centre is within walking distance, most women prefer to go to TBAs for delivery.

Some women claim they do not have the money to buy gloves and ‘kaveera’ – a polythene sheet. Both are required from every woman at every health centre, and even at the referral hospitals like Mulago. They cost Ush 3 000 (US$ 1.7).

“This problem has many facets. It depends on how you begin to tease it out,” said Sewankambo.

Midwife Nabuule says most of the women she has seen die at the ward are those who have unsafe abortions – usually young girls who use herbs, or metals hangers, and fail to abort the foetus. Others are women who indulge in extra-marital affairs, end up pregnant, and try a secretive abortion.

The high incidence of unsafe abortions is a leading cause of maternal morbidity and mortality. That alone could make it impossible for Uganda to attain the Fifth Millennium Development Goal of a 75% reduction in the maternal mortality ration by 2015.

A study carried out in Uganda in 2003 showed that an estimated 297 000 induced abortions, accounting for 54 out of every 1000 women of fertile age, and for one in five fatal pregnancies.

Health officials warn that at current rates, half of all Ugandan women will require treatment for complications related to abortion in their lifetime.

“Because women seeking abortions rely primarily on untrained personnel using unsafe methods, 85 000 women are treated for abortion-related health complications each year. Unsafe abortion is the country’s leading cause of maternal death,” claims the study by Sushreea Singh, Florence Miremb et al. [see READ ON].

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The study was conducted in 2003 in 313 health facilities that treat women who have post-abortion complications, and among 53 professionals who are knowledgeable about the conditions of abortion provision in Uganda.

The study demonstrated that nationally about half of pregnancies are unintended, and that 51% of married women aged 15-49 and 12% of their unmarried counterparts have an unmet need for effective contraceptives. The study concluded that the only solution is to help women obtain contraceptives to reduce the number of abortions. “Health care providers, advocates, professional associations, government and communities all have a role to play in ensuring women’s access to the contraceptive services they need,” Mirembe says.

Sewankambo says mothers and girls should be educated about the importance of delivering from a health centre. “This should be incorporated in the universal secondary education system,” he says.

But he argues that the problem is not only to do with poverty. “There is disorganization, lack of proper management and planning…. poverty is just a part of the problem. There are countries that are just as poor but doing better.”

The last decade has seen a slight improvement in the maternal mortality rate in Uganda. It stands at 505 deaths per 100,000 live births, compared with 537 in 1995. Recently the country made a commitment to reduce that further to 354 per 100,000 live births, a reduction of around 35%. This falls short however of the MDG goal of 75% by 2015.

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But he argues that the problem is not only to do with poverty. “There is disorganization, lack of proper management and planning…. poverty is just a part of the problem. There are countries that are just as poor but doing better.”

The last decade has seen a slight improvement in the maternal mortality rate in Uganda. It stands at 505 deaths per 100,000 live births, compared with 537 in 1995. Recently the country made a commitment to reduce that further to 354 per 100,000 live births, a reduction of around 35%. This falls short however of the MDG goal of 75% by 2015.

Primary problems for India’s TB

The highly motivated TB control programme in India relies on the health system - but it’s too weak to cope.

Primary health care in India must be revolutionized if the Revised National Tuberculosis Control Programme, launched in 1997, is to succeed. The story of a tuberculous woman, Hafeea Begum, who could not afford treatment and developed drug-resistant TB, illustrates why.

by Rupa Chinai

ASSAM, INDIA: When Hafeea Begum, age 28, was brought in a rickshaw to the Sipajhar Primary Health Centre in Assam, she was in a state of collapse. Hailing from a poor Assamese Muslim family in
Muslim Gopha village, around five kilometres from the health centre, Hafeeza was a case of relapsed tuberculosis. She represented the very patient that India’s Revised National Tuberculosis Control Programme (RNTCP) says it is targeting to detect and cure. But Hafeeza’s struggle to access this programme is a telling story of why India’s TB programme fails to reach those who desperately seek its help.

India’s northeastern states are amongst the most neglected in the country in terms of health services and basic development. An examination of the TB control programme in Assam provides an insight to why Indian health policy fails to make a difference in the lives of communities here or elsewhere. While millions of dollars are pumped into such stand-alone vertical health programmes, there is little hope of positive outcomes when there is no primary health care base on which they can stand.

India’s RNTCP managers claim they have a success story. A nationwide programme to detect TB patients and give them free drugs under the DOTS programme (Directly Observed Treatment – Short Course) was set in motion in 1997 at the behest of international donor agencies. In Assam it was launched April 2004. The programme envisaged a special focus on TB through the creation of a separate staff that would supervise and facilitate its implementation through the primary health care system. Improved methods of diagnosis and effective drugs promised a cure within six to nine months.

TB however, like most other illnesses, is rooted in a social context, say critics. Modern medicine considers itself impervious to the social factors that shape the health of individuals and communities. Technology and ‘miracle drugs’ have failed to deal with the roots of these illnesses, which lie in addressing issues of poverty and social environment. Besides, treatment delivery cannot be ensured at ground level when primary health centres remain empty shells and the community has no faith in its services.

Hafeeza had studied up to class 10, and was married off in 1996. Poverty led her parents to arrange a marriage with a man who already had one wife. What he really needed was a servant who served him without wages. He was also infected by TB, and Hafeeza contracted the disease from him.

In 2003, when her chest pain and coughing became unbearable, Hafeeza’s father took her for treatment at the main government hospital situated at Mangaldoi. The Sipajhar Primary Health Centre comes under the jurisdiction of Mangaldoi sub-division in Darrang district of Assam.

While the then prevailing National TB Control Programme prescribed a standardised regimen of five drugs (as does the present RNTCP), only two of these drugs were then available free from the hospital. The rest had to be purchased by the patient. Hafeeza received 45 injections over 17 days in the Mangaldoi hospital, but the cost of all the other drugs, plus the costs of transport, had already mounted to Rs 10 000 (US$ 250) and Hafeeza was forced to abandon treatment.

Feeling better initially, Hafeeza returned to the punishing regimen in her husband’s home, but two months later she was back where she had started. Afraid that he would be held responsible for her deteriorating health, Hafeeza’s husband sent her back to her parent’s home.

Hafeeza was now a ‘relapsed’ case of TB and had to purchase even more expensive, second-line drugs to which her TB bacillus had not developed resistance. Her plight was further compounded by the lack of public transport to reach health facilities. Defeated by such difficulties and having lost all faith in the government services, the family sought the help of the local ‘vaid’ (a quack). In the next months her condition declined further and she suffered severe loss of weight.

When she finally reached the Sipajhar Primary Health Centre in May 2005 and found succour through the Revised National TB Control Programme which was by then in force, Hafeeza represented the story of countless patients in Assam who were desperate to find a cure for TB – but for whom the divide between availability of TB services and access to it, has been impossible to bridge.

Says a TB programme manager in Mangaldoi, “This [RNTCP] is one of the best programmes in the world. The government is providing Rs 20 000 (US$ 500) worth of free drugs to each patient. We see the satisfaction of patients at the end of the treatment. If only we could get full cooperation from staff in the general health facility it would be a very successful programme”, he stresses.

Herein lies the nub of the problem. While the RNTCP has created a highly motivated and trained supervisory staff, improved diagnostic facilities through designated microscopic laboratories, and ensured availability of drugs through providing a separate box for each patient in the DOTS centre, its implementation is still largely dependent on the base of a strong primary health system. This does not exist in Assam, as in the rest of India.

The RNTCP depends on the primary health care centre outreach staff to detect new cases of TB; to ensure compliance of treatment; and to follow-up on defaulters. It depends on the primary health care centre doctor who has to clinically confirm the diagnosis and treat any side effects of the treatment.

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The primary health care centre’s staff meanwhile cope with a huge work burden imposed by a number of vertical programmes like ‘Pulse Polio’ vaccination or ‘Reproductive and Child Health’, which impose their own set of incentives and targets on them. Lacking training and motivation, the health staff focus on programmes that offer greater monetary incentives, are resistant to ‘walking the extra mile’ to detect or support patients, and are known to cook up false data.

Says an RNTCP official, “The lack of integration between the TB programme and the general health system is the main reason why the programme has not attained its goals. The PHC health staff do not support the TB programme because it does not offer cash incentives. These vertical programmes are creating distortions and there is no collaboration in the implementation of programmes”.

The degenerate work culture within the primary health system is evident across Assam. But it stands out in stark contrast to the high level of motivation seen in the RNTCP staff, who have undergone systematic training and regular refresher courses...

This opinion is an edited version of one first appearing in InfoChange News & Features: www.inforchangeindia.org

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