#### PLENARY PRESENTATIONS

#### Information For Malaria Control In Africa : Are We Ready?

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First, I wish to congratulate the organizers of the MIM Malaria Congress for putting the issue of Information and Communication so prominently on its agenda. Of the 30 plus sessions this week, at least 8 are fully or largely dedicated to health information systems and connectivity in support of malaria control. This is highly refreshing for a disease specific conference and I hope we can all make best advantage of this rare opportunity. I also want to thank the organizers for inviting me to tackle this topic and to be provocative. But from the outset, I must also warn you that I am not an information systems specialist. Like most here, I am a health professional working in Africa and I approach the subject from that perspective. And like most of us, whether coming from malaria research or malaria control, we must be interested in evidence and information on which to base the way forward and to monitor our progress. So I hope that what I have to say will have resonance with many of you.

## In public health there are three things that we always complain of not having enough

- The first complaint is that there is never enough **time**. The clock is always ticking. Our most frequently used measures of health and disease are time based, be they time denominated epidemiologic rates or more recently, DALYs, Years of Life Lost, or Years Lived with Disability. For those focussed on malaria, even if we take the lower estimates of malaria mortality in Africa such as those in Murray and Lopez' Global Burden of Disease Analysis, or Bob Snow's more recent estimates of malaria mortality in the current issue of Parasitology Today, still over 10,000 Africans, mainly children and pregnant women, will die due to malaria during the 4 days of this MIM Conference. Time will always be against us.
- The second complaint is that there are never enough **resources**. The magnitude of the burden of disease in the world everywhere, but especially Africa, always outstrips available resources to respond adequately. Resources are always finite and constrained. Choices must be made. But more and more, these choices are being made on the basis of evidence and information rather than in the past where priorities have been set largely on the basis of common sense, albeit often poorly informed common sense, tempered by inertia, by last year's budget, by last year's epidemic, by donor paradigms, by special interest groups, by politics, and by funding opportunities rather than program needs. When resources are inadequate, allocation decisions must be supported by information and evidence.
- The third complaint is that we never have enough **information**. At least the information we need. And this is the issue that I have been asked to deal with during this half hour.

Of these three deficiencies: time; resources; and information, time will always be against us; and resources will always be constrained, but information could be different. We are on an exciting threshold. The ease and pace at which we can capture, store, manipulate, and

communicate information is accelerating at a phenomenal rate. Unlike the costs of new anti-malarial drugs (and just about everything else in life), the real costs of managing and communicating information are actually dropping, and dropping fast. There are few things that have decreased in price as steadily and dramatically as the cost of storing a megabyte of information on our desktop. This has dropped about 50% per year, every year, over the past 15 years. On the information sharing front, at least for the research side of the malaria battle, e-mail can now reach field research settings such as Navrongo, Ifakara, Kilifi and many others. Several Ministries of Health in Africa already maintain their own Web Sites. For some of us there is already information overload. But is it the information we need to do the job at hand? To roll back malaria?

So, I am not going to talk about the many, still under-exploited opportunities that Information Technologies bring us. Instead, I would like to focus on the information itself, the actual sources of information for decision making.

This Conference bears witness to the fact that there is now a high level of political will to deal with malaria at the international level. We have MIM. We have Roll Back Malaria. We have the African Initiative for Malaria. We have a growing number of African networks against malaria (MARA/ARMA, EANMAT, INDEPTH to name a few). But we still do not have the necessary political will to Roll Back Malaria at the National, District, and Community levels in much of Africa.

What are the information needs to turn that corner? To mount a societal response to malaria proportional to the magnitude of the problem. What information is available? Is it what we need? What is missing? What are the new opportunities for information relevant to malaria control on the near horizon?

I will try to tackle this in two parts: the first focussing on what data sources we have now for evidence-based planning for malaria control; the second focussing on what information we need to measure our progress in reducing the burden of malaria.

#### 1. Available Conventional Sources of Information for Malaria Control

There is not time to review all conventional sources of information for malaria control. So I would like to highlight only those that are available in the absence of a malaria control program. Where specific malaria control programs are already running well, their internal information systems are usually sufficient. But for most of Africa where integrated malaria control strategies are taking off, information just needs are more acute.

#### Conventional Sources of Information for Malaria Control

- Routine Malaria Control Program Data
  - Vector Control
    - Active & Passive Case Finding
- Routine Health Services Data
  - HMIS
    - Standardized Hospital Reports
- Research
  - Survey Data
    - DHS
      - Community & Household Surveys
      - Health Facility Surveys
      - Rapid Appraisal and Needs Assessment Exercises
    - Intervention Trials

#### 1.1 Routine Health Services Data

#### 1.1.1 HMIS

Let me start with the most commonly accessible information for the health system. This traditionally comes from the system's own health facilities. In the past this took the form of routine annual reports from health facilities and it was implicitly assumed to reflect the state of the health problems of the population. More recently, many countries have made efforts to systematize the collection and use of health facility data. They do this by applying health informatics to develop a Health Management Information System reaching down to the peripheral health facility level. The general purpose of such systems is to enhance quality of care, facilitate accountability, and assist cost containment. They usually do so by applying a hierarchy of:

- a. Transaction Processing at the Facility and District levels, feeding into :
- b. Management Information System at the Regional and National Level; followed by:
- c. Decision Support back to District and Facility Level

Unfortunately most of the energies of HMIS go into transaction processing, rather less into the Management Information System, and least into the Decision Support back to the periphery. We see volumes of forms filled at facility level logging attendances, diagnoses, prescriptions, follow-ups, and referrals. These transactions are fed up the line to District, regional and national levels where at each stage, they are collapsed aggregated and into summary statistics. Yet very little

#### Health Management Information Systems HMIS

- HMIS applies Health Informatics to:
  - enhance quality of care
  - facilitate accountability
  - assist cost containment
- Through a cycle of:
  - Transaction processing at Facility and District Levels
  - Management Information System at Regional and National Levels
  - Decision Support back to District and Facility Level

comes back to the Districts, and virtually nothing comes back to the thousands of health facilities who continue generating information daily. In addition, the HMIS data are often incomplete due to under-reporting from HMIS facilities, and non-reporting from private and traditional facilities.

But there is a more serious deficiency in HMIS data sources. Even if the HMIS cycle were to be fully functional, the utility of facility based data for estimating population health and monitoring progress is highly questionable. Such data are easily biased by the quality of services; the availability of drugs and supplies; the performance of health workers; the physical and social access of the population; the local mix of governmental, non-governmental,

#### Malaria at Facility Based HMIS National Statistics for Tanzania

• MALARIA is:

• Leading Case for < 5 admissions 49% Malaria at Facility Based HMIS for Morogoro, Tanzania

#### **District Statistics**

- Malaria is:
  - Leading cause of health service attendance
  - 30% of attendances (285,037 in

traditional, and private health services; user fees and other consumer costs; and most importantly, the health seeking behaviours of households. But is this a problem for malaria data?

Health facility data in Africa often cite "30% of out-patient attendances are due to malaria". But given the chronic under-support of malaria control across Africa, such data are evidently of limited practical value and certainly have not provided sufficient lobbying clout for Program Managers to set priorities or compete for resources, either at the National or local levels.

Despite malaria's dominance in the HMIS statistics, the District Health Plan priorities in this illustration failed to mention malaria, although they did specify resources for 11 other diseases including dental caries and hepatitis B. The District response to malaria defaulted passively to the anti-malarial content of the Essential Drug Kit, which amounted to only 5% of the intervention budget of the District. I suspect the same is true across most Districts of Africa, at least those fortunate enough to have an essential drug program.

And as for monitoring change in health status, can we really use facility based statistics? How do we interpret an increase in attendance? Is it due to improved quality and utilization of services, or due to an increase in community disease burden.

#### 1.1.2 Standardized Hospital Record Reports

Another source of data is Standardized Hospital Reports. For severe and complicated malaria, hospital admission data may be better than routine peripheral HMIS data. Certainly changes in hospitalisation over time, numbers of blood transfusions conducted, and case-fatality rates should indicate changes in severe disease patterns in a community. Age-patterns of severe disease may provide insights into locally acquired immunity patterns. Seasonal patterns of severe disease can indicate opportune times for intervention. These data are available, although subject to some degree to the same biases as routine health service data. But there are few examples of the routine use of hospital data for planning and designing interventions. Perhaps standardized reporting from sentinel hospitals could go far to supplementing an HMIS with more relevant burden of disease information.

On the whole, it is very difficult to determine the costs of a comprehensive, system wide, HMIS, just as it is difficult to determine the benefits. However the costs are substantial because large numbers of facilities and event transactions are involved, and the benefits, at least for understanding the community impact and dynamics of malaria and other diseases, are marginal. Could some of the effort and cost of generating facility data every where be re-directed to collecting more relevant, higher quality data in sentinel sites to be shared appropriately? One idea might be to strip down HMIS only to indicators required to manage that facility efficiently and re-allocate the freed resources to something else. I will come back to what that something else could be later.

In any case, much work is required to examine the real value of HMIS data for District-level planning and impact assessment.

#### 1.2 Research Data

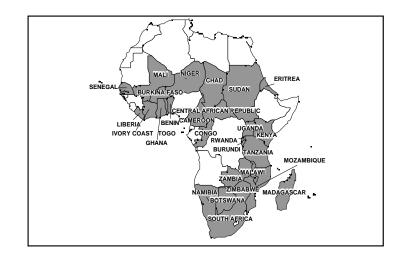
#### 1.2.1 Survey Data

The next commonly available source of information for malaria control falls under the research heading. These have traditionally come from cross sectional survey data, of which there are various sources.

## National Demographic and Health Surveys (DHS)

National demographic and health surveys are now conducted every two years in 29 countries in Africa. These are routinely conducted on

## Demographic and Health Surveys in Africa 29 Countries by 1999



large nationally representative samples. For example, the last DHS survey in Tanzania involved 8,000 women. However samples are usually too small to allow sub-regional analysis. This is a limitation since most health reforms are decentralizing decision making to the District level at which the national DHS sample is too dilute. But the main limitation of the DHS data for the focus on mortality is that they employ indirect methods, and thus reflect the mortality pattern in the past, on average 3-5 years ago, but do not reflect contemporary burdens and impacts. Nevertheless, over time, the DHS can provide a broad picture of trends in infant and childhood mortality. But on the knowledge, attitudes and practice side, the DHS surveys offer abundant opportunities to conduct nationally and regionally representative polls of behaviours. DHS surveys often contain elaborate questions on family planning practices, respiratory diseases, diarrhoea management, etc. but have only superficial questions if any dealing with malaria, Recently, a more detailed DHS survey module on malaria is under-development. Should we, as a malaria community be influencing sampling and questions within national DHS survey instruments? For example, it would be relatively easy to develop questions which elucidate trends in bednet ownership, knowledge of net treatment benefits, source of anti-malarials, etc..

#### Cross Sectional Household Behaviour Surveys (impact surveys)

I now turn to non-DHS household surveys. HMIS style Information systems usually ignore health seeking behaviour and I will illustrate the consequences of that shortly. However, standardized, stratified, population proportional, cluster sample survey methods and instruments have recently been developed for the IMCI package which illuminate many important aspects of household health seeking behaviour in relation to childhood illnesses including malaria, and malaria preventive practices at home such as ITNs. These are best conducted as repeated cross-sectional surveys every few years in strategic locations where impact and trends need to be assessed. The cost is approximately 10,000 USD per survey and thus they are not for routine surveillance or HMIS.

#### Health Facility Multi-indicator (process surveys)

Based on the UNICEF surveys, similar cross-sectional surveys are being developed to document process change at health facility level for IMCI. These can be conducted in lock step with the Household Behaviour Surveys at marginal extra cost.

#### 1.2.2 Intervention Trials

Still under the research heading, one of the most informative sources of data we have for malaria in Africa has come from demographic surveillance (DSS) mounted by the research community to test intervention efficacy for mortality reduction. Beyond providing objective evidence of intervention efficacy, these systems provide deep and unique sources of information on burden of disease. Just as intervention research in the form of removing the mythical Broad Street pump handle in London in the 1830's taught us much about the epidemiology of cholera, so too has the intervention research in the form of randomised field trials of insecticide treated nets in Africa in the 1990's taught us much about the epidemiology of malaria. One result has been that the direct and indirect burden of malaria was shown to be much higher than expected. Almost all prior estimates placed malaria at 10% of under five mortality, yet the ITNs prevented 20 - 30% and in some settings even more of the under five mortality. This has gone far to re-shape our appreciation of the importance of preventing malaria. However, well designed intervention trials of sufficient size to document mortality are few and far between and cannot be counted upon to contribute routinely to national information systems.

#### 1.2.3 Rapid Needs Assessment Exercises

Finally under the research heading, there are the needs assessments and situation analyses for malaria control. These have tended to be quick, often ad hoc, in and out exercises which collate but rarely produce new information. However, given the paucity of reliable malaria data at the national, district and community levels, Roll Back Malaria is developing a tool kit for a complete needs assessment. This assessment can be conducted within the space of a few months to assemble systematically all the necessary information to determine the scope and needs for integrated malaria control. This tool is currently being piloted but is an innovation that may prove very useful to mobilize both the political will and resources at national and sub-national levels. Those interested in this can subscribe to an active list serve sharing the methodology.

So, summing up the conventional sources of information for malaria control, we find that all the approaches have important deficits. What we need to do is avoid the bias and low quality of facility based data; avoid the lack of District specificity and contemporary relevance of the DHS burden data; and avoid the patchiness and low coverage of survey data, research trial data, and rapid assessments.

#### 2. Emerging Sources of Information for Malaria Control

So what new sources of information could provide timely data of sufficient coverage and quality to advocate for, plan and allocate malaria control resources and to monitor progress in averting the mortality and morbidity associated with malaria? Here I would like to highlight just two new areas in which international networks have emerged very recently.

#### 2.1 Spatial and Environmental Information Systems.

The first of these can be collected under the heading of Spatial and Environmental Information Systems. These information systems include the use of Geographic Information Systems (GIS) to map populations at risk in relation to their health risks, their health services, and their health programs as exemplified by the work of Health Map at WHO.

There is also the work of MalSat, NASA, and MARA / ARMA and others to harness satellite remote sensing data and other climate data in the service of malaria epidemic prediction in the highlands and other areas of unstable malaria in Africa.

Finally, there is the malaria specific work of the MARA / ARMA collaboration which seeks to map malaria transmission risk down to 5 km resolution across all of Africa. It is also developing a continental, spatial database of all pertinent malaria indices on burden of

malaria. transmission risk, entomology, drug and insecticide resistance, etc. As an example, here is one MARA risk map for Tanzania illustrating the kind of heterogeneity that exists, even at the sub-District level. We need to examine how the availability of such new perspectives on malaria will influence malaria advocacy, resources and programs at National and sub-national levels for malaria control. Since you will hearing more about MARA later in this session I will not go into further detail.

## Emerging Sources of Information for Malaria Control

- Spatial and Environmental Information
  Systems
  - Health Program and Population Mapping
  - Satellite Remote Sensing for Epidemic Forecasting
  - GIS Modeling and Malaria Risk Mapping
- Sentinel Demographic Surveillance Systems
  - Community based burden of disease and trends

Instead I will focus on the second potentially emerging source of information for malaria control, the idea of sentinel demographic surveillance for mortality and other indicators.

#### 2.2 Sentinel Surveillance Data

First, why mortality? According to DALY estimates, malaria is one of the first and largest components of Africa's burden of disease. 90% of the malaria DALY in Africa is contributed by premature mortality as Years of Life Lost, the YLL component. Only 10% of the malaria DALY is years lived with disability or YLDs. Even so, malaria is the fourth ranked cause of disability or YLD's in Africa, such is the magnitude of the problem. Interventions that prevent malaria mortality also prevent malaria morbidity. Indeed Christian Lengeler's Cochrane meta-analysis of randomized controlled trials concludes that ITNs reduce overall child mortality by 18% and morbidity by 48%. Since 90% of the malaria DALY is premature mortality, we must measure mortality to assess properly the effectiveness of our strategies. The problem is that in Africa, vital event registration or cause of death data in any routine information system is rare. However, as we have seen, Demographic Surveillance Systems have been used to measure mortality efficacy in trials. Can the same DSS approach be used to influence priority setting and measure effectiveness in real life programming? Perhaps yes.

Here is an example of а Tanzanian District which, in 1996 had a health facility within 5 km of 85% of its population, was allocating 5% of its budget to malaria, was treating over a quarter of a million malaria cases per year and thought it was on top of the malaria problem, at least according to its facility-based HMIS. Then a Demographic District Surveillance System (a DSS) was introduced through a DFID funded Morbidity and Mortality

Community Based Burden of Disease Data -Insights from Sentinel Demographic Surveillance (DSS)

- Although 85% of households are within 5 km of a health facility...
- 83% of all deaths occur at home
- 84% of <5 deaths occur at home
- · 30% of total mortality burden is due to malaria
- 45% of <5 mortality burden is due to malaria
- 46% of deaths at home occur without prior health facility contact
- 90% of deaths due tocute febrile illness with seizuroccur at home

- Source: Tanzania Ministry of Health and AMMP Team, 1997.

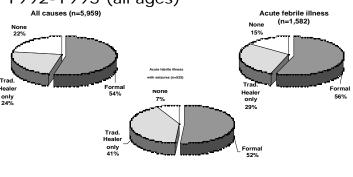
Project which revealed a completely new and disturbing picture of the real burden of disease as experienced by the community.

It showed that:

- 83% of all deaths occurred at home, including child deaths and were not counted in any HMIS
- 30 % of the total, and 45% of the child mortality burden was due to malaria

But more disturbingly, despite high facility attendance:

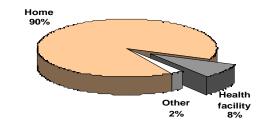
- 46% of all deaths, including malaria deaths, occurred without prior contact with a health facility Contact with Formal Health Facilities in the Illness Leading to Death, Morogoro (R), 1992-1995 (all ages)



Based on: "The Policy Implications of Adult Morbidity & Mortality: End of Phase 1 Report" (1997) Tanzania Ministry of Health & AMMP Team, Dares Salaam.

- 90% of child deaths due to acute febrile illness with seizure occurred at home.

The District was shocked by 1) the degree of mortality outside the system, and 2) the degree of underutilization of its health services for severe and complicated malaria (despite high coverage and high attendances for simple malaria). As one Ministry official put it, *"our facility based HMIS only showed us the nose of the hippo that was hidden beneath the water*". Place of Death in Children Under 5 years from Acute Febrile Illness with Seizures Morogoro (R), 1992-1995



Based on: "The Policy Implications of Adult Morbidity & Mortality: End of Phase 1 Report" (1997) Tanzania Ministry of Health & AMMP Team, Dares Salaam.

What was the District response to this new appreciation from a community based DSS information system?

Unlike previously available HMIS attendance data which indicated ineffectively that malaria was a top priority, the policy and advocacy influence of these community based mortality statistics was swift.

the share of resources directed to malaria control and а 20-fold increase in the share of resources for malaria control for children under 5. The District adopted and introduced IMCI in all its health facilities and now promotes social marketing of ITNs. Malaria is now, for the first time, given a prominence consistent with its disease burden in District Health Plans. The District DSS will be used continues and to document how these investments and strategies operate to reduce the burden of disease.

#### So what is a Demographic Surveillance System and how much does it cost?

A typical DSS is simply a geographicallydefined, population, usually in the order of 100,000 people in which 40 to а longitudinal surveillance system documents births. all deaths. and migrations. It does so by conducting an initial census followed by re-enumeration

# MorogoroDisease Burdenvs 96 Budget Priority

As you can see in these comparisons between 1996 and 1998, there was 5-fold increase in

#### <sup>35%</sup> <sup>30%</sup> <sup>30%</sup>

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98 Budget Priority

DSS: What is it?

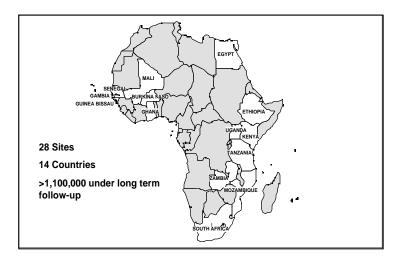
- Demographic Surveillance System
  - A geographically-defined population under continuous demographic monitoring with timely production of data on all births, deaths, and migrations (INDEPTH, 1998)
- How does it work?
  - enumeration of denominator population by repeated household visits at regular intervals
  - continuous reporting of numerator vital events by community key respondents
  - cause of death determined by verbal autopsy
  - rigorous supervisory, quality control, and data management systems
  - Sentinel DSS annual cost estimated at < \$0.03 per capita</li>

up-date rounds at frequent intervals, at least annually if not quarterly, to determine the denominator at risk, especially young children. At the same time, a parallel system of community key respondents continually identify the numerator vital events of births and deaths. All deaths are followed up by a surveillance system supervisor who conducts a verbal autopsy to ascertain the cause of death. DSS systems have rigorous supervisory, quality control and data management systems in order to link events in the numerator to the population in the denominator. A single DSS in a rural African sample population of 100,000 will document cause and prior health seeking behaviour in an average of about 5 deaths per day. Unfortunately many of these deaths will be due to malaria.

How much does all this cost? To run six such DSS systems in a large country like Tanzania and using a stratification to distribute annual DSS results to Districts represented by their sentinel will cost less than 3 US cents per capita per year with present methods. UNICEF is working on a variation of village registers for vital event registration that might lower the costs of DSS even further.

Because DSS provides quality data on household burdens of disease and a platform for a wide range of health. social. economic and behavioural analyses that can not be obtained in any other way, there has been an upsurge in DSS applications in recent years. In recognition of this, over 40 DSS field sites in the developing world have recently created а collaborative international network called INDEPTH. Its purpose is to harness the full potential of such sites,

### DSS Field Sites in Africa - 1998



increase their technical efficiency, lower the costs of the methods, and maximize the policy influence of the information generated. In Africa, there are already 14 countries and over 1.1 million people under continuous follow-up by DSS in 28 field sites. In Tanzania, there are DSS systems running in 6 rural and 2 urban Districts. Tanzania will be the first country where the idea of sentinel DSS sites in a national HMIS will be tested. The INDEPTH network has established a Malaria Task Group led by the DSS site at Manhica, Mozambique, to assist the 27 African DSS field sites working in malarious areas.

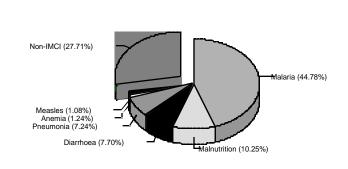
## But can DSS be used to monitor the effectiveness of strategies to roll back malaria?

Roll Back Malaria is not advocating vertical, malaria only approaches. It is talking about broad system wide changes and integration. Integrated Management of Childhood Illnesses (IMCI) is a case in point. The effectiveness of IMCI will be determined by a myriad of operational and behavioural features including coverage, utilization, provider and user compliance, diagnostic accuracy, efficacy of the anti-malarial drugs, referral, etc. If IMCI is effective, we should see a reduction in proportional IMCI preventable mortality, even if other causes such as HIV are to increase. Within the IMCI causes, the non-specificity of verbal autopsy for malaria is no longer an issue. Because the DSS documents all mortality, we are able to see shares of the whole. To have plausibility in attributing a decline in IMCI preventable mortality to IMCI effectiveness, we need to document process indicators relevant to IMCI by linking the IMCI household and health facility surveys into sites where the DSS sentinels operate. An INDEPTH Collaboration of four DSS sites, two with IMCI and two without IMCI is piloting this approach now in Tanzania.

#### Under 5 Burden of Disease - Morogoro YLLs Addressable by IMCI

#### Conclusions

In conclusion. To sum all this have important up, we HMIS deficiencies in and survey style information If there is one take sources. home message I want to emphasize, it is that sentinel surveillance of all cause household mortality at the level through DSS may be our



Source: Tanzania Ministry of Health, AMMP and TEHIP Teams, 1998

best chance 1) to obtain the least biased picture of current, initial malaria burdens and critical utilization behaviours; 2) to influence national policy and resources for integrated malaria control; 3) to document trends in disease burdens over time; and 4) to monitor effectiveness of Roll Back Malaria strategies.

But this still leaves the question of who should take ownership of health information for RBM - whether it be a DSS approach, or conventional HMIS, DHS etc. Most national information systems necessarily operate to support a wide sectoral requirement. Most of the interventions proposed to RBM at the national level will not be "malaria-specific" - for example, management of anaemia in pregnancy; management of childhood illnesses; improved drug-supply and rational prescribing, etc. Information, whether on process indicators or impact assessment, will be cross-cutting and demand ownership by, and integration into the wider health sector. Where then does the responsibility for malaria information lie and how can this be supported to meet the needs of RBM? RBM will be a component of improvements in health service delivery generally and therefore this raises the issue of who should drive Health Information Systems for Roll Back Malaria at country level.

As a closing perspective on this. We must accept that we will never have all the time, resources and information that we would like. But we may be able to re-allocate some of our existing time and some of our current resources to generating community based information on the burden of mortality and on health seeking behaviours specifically associated with this burden. These are two of the most important statistics which we must influence and monitor. Since most of the disease burden in Africa is under-pinned by malaria, we must push for and explore such re-allocations. Re-allocation of some resources from comprehensive, facility based MIS, to a sentinel, community based DSS system may emerge as our most cost-effective option.

As long as malaria tops the burden of disease in Africa, we, as the malaria control community, must not shy away from a role as "pathfinder" to strengthen Health Information Systems in Africa.