## INDEPTH Network

#### 7th INDEPTH Network Annual General and Scientific Meeting

3 to 7 September 2007, Safari Park, Nairobi, Organised for INDEPTH Network by Nairobi, Kilifi and Kisumu DSS Sites in Kenya

#### Theme:

The role of Demographic Surveillance System (DSS) in monitoring progress towards the Millennium Development Goals (MDGs)

## **Conference Report**



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### 1 Introduction

#### 1.1 Period and venue

The 7th INDEPTH Network Annual General and Scientific Meeting was held in Nairobi, Kenya from 3 to 7 September, 2007 at the Safari Park Hotel and Casino. The five day meeting was hosted on behalf of the INDEPTH Secretariat by the Nairobi, Kilifi and Kisumu DSS sites in Kenya.

## 1.2 Theme of the conference

The theme of the 7<sup>th</sup> INDEPTH Network Annual General and Scientific Meeting was: "The role of DSS in monitoring progress on the Millennium Development Goals".

The following were the sub-themes of the meeting:

- 1. . Using DSS to monitor poverty dynamics.
- 2. Using DSS to monitor progress in education.
- 3. Using DSS to monitor progress towards reduction in child mortality.
- 4. Using DSS to monitor progress towards improvement in maternal health.
- 5. DSS and the HIV/AIDS epidemic.
- 6. Using DSS to monitor malaria control programmes.
- 7. Using DSS to monitor disease control programmes.
- 8. Using DSS to monitor impact of environmental change on humans.
- 9. Technical innovations from DSS sites.

## 1.3 Participants

The meeting brought together leaders of the INDEPTH Network, young and senior scientists from demographic surveillance sites in developing countries and many other international participants from the scientific donor community.

A total of 175 participants attended the meeting. Participants included, among others, site leaders (28), young scientists (9), presenters oral and poster (80), SAC members (8), board members (8), INDEPTH Secretariat (9) and funders including the Wellcome Trust, the Bill and Melinda Gates Foundation, and SIDA/SAREC (3). The Government of the Republic of Kenya was represented by the Ministry of Planning and National Development. The Minister, Dr. Henry Obwocha, was the guest of honour at the opening ceremony of the meeting on Monday 3 September, 2007.

#### 1.4 Activities

One hundred and twenty five abstracts were submitted after the call for abstracts. Of these, thirty-eight (38) were selected for oral presentation while forty-two (42) were poster presentations.

Due to the very large number of papers, the presentations were organised into twelve (12) plenary sessions and eight (8) parallel sessions. Apart from these, there were several special and side sessions that covered special areas of the INDEPTH Network. A total of forty two (42) posters were displayed at the meeting. The poster sessions were organised into daily themes that followed those of the oral presentations of the day.

A well attended reception was organised on the evening of Sunday 2 September, 2007. On Tuesday evening the participants attended a dinner at the world famous Carnivore Restaurant known for its

game meat. The conference ended with a field visit to two Nairobi DSS sites, Korogocho and Viwandani on the afternoon of Friday 7 September 2007

This report will be presented by day and session.

## 2 Day 1, Monday 03 September

## 2.1 Plenary 1- Opening Session

## 2.1.1 Keynote - Linkage between MDGs and DSS Speaker: Dr Alex Ezeh, Executive Director of APHRC

The Keynote speech was delivered by Dr. Alex Ezeh, Executive Director of the African Population and Health Research Centre (APHRC). He noted that there were 8 goals with 18 targets, over 48 indicators and over 110 measures. He mentioned some highlights of the 2007 MDG report as follows:

- Target 3:
  - "sub-Saharan Africa (SSA) is making progress towards universal enrolment but has a long way to go"
- Target 5:
  - "Child survival rates show slow improvement, and are worst in SSA"
- Target 6:
  - "Half a million women continue to die each year during pregnancy or childbirth, almost all of them in SSA and Asia"
- Target 7:
  - "HIV prevalence has levelled off in the developing world, but deaths from AIDS continue to rise in SSA"

Dr. Alex Ezeh noted with concern that data sources for the 2007 MDG report were from regional/sub-regional figures compiled by IAEG on MDG indicators, reports of countries to different UN agencies which are often modified by the agency, or were weighted by country population size and relied partially or only on censuses and national survey data such as the Multiple Indicator Cluster Surveys (MICS) and Demographic Health Surveys (DHS). Unfortunately, such regional/sub-regional averages were often based on only a few countries.

He stressed that measuring MDG progress required timely, accurate and comparable statistics repeated regularly; and the data needed to be divided into administrative, social and economic groupings. Existing data sources did not meet these requirements and were therefore less useful for decision making and resource allocation.

Dr. Alex Ezeh cited lack of vital registration data as another big challenge and obstacle to monitoring the MDGs in SSA. For example, only 4 out of 46 countries in the region had recorded usable cause of death data from their vital registration system to WHO, in December 2003. Also, according to mortality data by cause (1995 onwards) available in WHO, coverage of death registration was less than 50% in SSA.

He said that this had serious repercussions and were a big hindrance to overall development on the continent. "As a result, in Africa people are born, live, and die with no records of them. We are always piloting interventions with minimal scale up, interventions are rarely rigorously evaluated, and health continues to worsen in many areas," he observed.

Dr. Alex Ezeh informed the meeting that DSS sites continuously produced data on births, deaths, and migrations within geographically defined populations and could accurately measure these at individual, household and community levels. Compared to other surveys using smaller population samples (Median of 7,060), DSS sites followed up larger population samples, mostly more than 60,000 people. They therefore had the potential to provide needed information annually and to consider disparities in standards between the rich and the poor. Further, he added that DSS could show poverty dynamics within households and could provide the context of such indicators.

He underscored the importance of generating such data adding that, "It's not because countries are poor that they cannot afford good information, rather it is because they are poor that they cannot afford to be without it."

#### 2.1.2 Opening remarks

### Speaker: Hon. Henry Obwocha, Minister for planning and National Development, Kenya

The meeting was officially opened by the Minister for Planning and National Development in Kenya, Hon. Henry Obwocha, the guest of honour. He called on the international community to build a stronger and more broad-based global recovery, address imbalances and strengthen long-term fundamentals to achieve the Millenium Development Goals.

The minister said that Kenya initiated the implementation process to achieve the MDGs in 2002 and among the challenges facing the country towards this end was a lack of resources and availability of data. "A detailed assessment of the progress of the MDGs is inhibited by the scarcity of relevant data," he noted. He stressed that the goals as adopted in 2000, were ambitious and would require significant efforts by the countries and all development partners to realise the 2015 deadline.

Hon. Henry Obwocha highlighted the progress Kenya had made in its effort to meet the targets, noting that the country had recorded significant progress in realising *Goal 2*, on achieving Universal Primary Education. Boys and girls were able to complete primary schooling nationally with the provision of Free Primary Education, and to ensure successful transition, he reported that the Government had set up plans to provide free tuition at secondary school level as from 2008. He further observed that there had been remarkable progress made on meeting *Goal 6*, on Combating HIV/AIDS, malaria and other diseases as HIV prevalence in the country had declined from 7% in 2003 (KDHS) to 5.9% in 2005 and was currently (in 2007) estimated at 5.1%. Also, the use of Insecticide Treated Nets (ITNs) and access to relevant information, education and communication for all the people at risk had reduced cases of malaria infections and death.

The Minister summarised progress on the other goals as follows:

**Goal 1**: **Eliminate Poverty and Hunger** - The proportion of people living below the poverty line had declined from 56 % in 2002 to about 46% in 2006. This decline was recorded in both rural and urban areas. The rural areas recorded declines from 52.9% to 49.1%, while urban areas recorded declines from 49.2% to 33.7% in the period 1997 to 2006, respectively.

Goal 3: Gender Equality and Women's Empowerment - Despite near-gender parity in the primary education cycle, sustainable campaigns and other gains on gender issues, wide gender gaps

still existed as women lagged behind in labour participation, positions of leadership and power and also in levels of higher education. The Government hoped to build on the one-third reservation policy towards parity that was being availed to women within the Vision 2030 implementation period.

Goal 4: Reduce Child Mortality – Regrettably, the trend had risen from 112 per 1000 live births in 1998 to 115 in 2003 (Kenya Demographic Health Survey, KDHS 2003). To address this, the Government, in collaboration with the WHO and UNICEF, was implementing the Integrated Management of Child Illness (IMCI) strategy which combined better management of childhood illness with nutrition, immunization, maternal health and other programmes. The Government was also increasing funding for health and related sectors to achieve the MDGs.

**Goal 5: Improve Maternal Health** – Maternal mortality rate figures were estimated at 670 per 100,000 live births in 1990, 590 in 1998 and 414 in 2003 (KDHS). Despite concerted efforts to improve maternal health, the proportion of mothers assisted by skilled health personnel at delivery had declined from 51% in 1989 to 45% in 1993 and 42% in 2003. Efforts were under way to reverse this trend, with key strategies to put in place policies and programmes that would provide education to men and women on safe and comprehensive motherhood.

**Goal 7: Ensure Environmental Sustainability** – The target for this goal was to integrate the principles of sustainable development into the country's policies and programmes to reverse the loss of environmental resources. The Government had put in place a broad framework to mainstream the environment into national and sectoral planning.

Goal 8: Develop Global Partnerships for development – The Government had set in place strategies to address declining Official Development Assistance (ODA) through improved governance measures and reforms aimed at enhancing Foreign Direct Investment and Trade, among other priorities.

The Minister outlined data sources for these indicators: the Government and non-Governmental organisations, surveys such as the Kenya Demographic and health Surveys (KDHS), the Welfare Monitoring Surveys (WMS), annual Economic Surveys (EC) and the Kenya Service Provision Assessment Surveys (KSPA) conducted by the Ministry of Planning and National Development with the Ministry of Health. Supplementary data had also been obtained from the Population Council, African Population and Health research Centre, (APHRC), Kenya Institute of Public Research and Analysis (KIPPRA), and other NGOs.

Hon. Henry Obwocha stressed the need for strong partnerships between the developed and developing countries as this was crucial for progress, adding that good development outcomes called for accelerated growth and stronger focus on the needs of the poor in the development process. He reiterated that developing countries were in need of relevant data and information to call for support from the International Community. "To be pragmatic, institutional frameworks will need continuous strengthening for relevant, timely data and information. Demographic and Health Surveillance Systems can provide information for monitoring progress towards the MDGs targets," he emphasised.

The Minister acknowledged with gratitude the work of the APHRC in the twin fields of Population and Health, especially in the Nairobi slum areas, and urged the organisation to engage more with the National Coordinating Agency for Population and Development (NCAPD) and the Kenya National

Bureau of Statistics (KNBS) and other allied organisations to share research information as this was indispensable for relevant policy formation and programme development in the effort to achieve the MDGs in Kenya.

## 2.2 Plenary 2 - INDEPTH Network Activities 1

This session comprised four presentations based on cross-site capacity building and working group activities:

- 1. Fostering Partnerships in DSS Sites for capacity building in research for Programme Planning: Margaret Gyapong (Dodowa DSS)
- 2. Adult Health the INDEPTH-WHO/SAGE Initiative: Steve Tollman (Agincourt DSS)
- 3. Migration and Health. Understanding dynamics of migration and urbanisation at INDEPTH Sites: Mark Collinson (Agincourt)
- 4. Developing a Prototype for Cross-Site Data Sharing among Demographic Surveillance Sites. Sanjay Juvekar (Vadu DSS)

The first presenter, Margaret Gyapong of Dodowa DSS in Ghana, presented work that she and her colleagues from the Navrongo and Kintampo DSS sites in Ghana are collaborating on. The focus of her presentation was a collaborative initiative the sites were pursuing with funding from INDEPTH to foster partnerships in DSS capacity building in research of programme planning and utilisation for policy.

The collaboration was motivated by the fact while doing similar work, the sites had not been collaborating with each other. Also, there was little knowledge of the utility of DSS data within the Ghana Health Service (GHS) although these sites were under the service.

Based on these shortcomings, the sites decided to conduct site visits and needs assessments to identify possible cross-site activities. They also held stakeholder meetings with staff of the Ministry of Health and the Ghana Health Service. They met with the Director of Research and managed a presentation at the senior managers' meeting of the MOH/GHS.

The conclusion from that meeting was that many of the managers had no knowledge of what was going on at the DSS sites.

Based on these discussions, the three sites then collaborated on a study on community acceptability of Artesunate-Amodiaquine for the treatment of uncomplicated malaria funded by the INDEPTH Network and the National Malaria Control Programme. That study had been completed and, based on its results; the National Malaria Control Programme had requested the sites to submit a proposal for further work. A proposal had now been developed which the National Malaria Control Programme was willing to fund.

The second presentation was by Steve Tollman of the Agincourt site in South Africa. The presentation gave an overview of progress made by the Adult Health and Aging Working Group. He noted that the aim of the Adult Health and Aging Working Group was to understand transitions in adult health and aging. He stressed that adult health and aging issues were rising in sub-Saharan Africa and Asia, causing great concern to many scientists.

According to Steve Tollman, the working group had made great progress. Eight INDEPTH sites were involved in the work, with three fielding the full WHO-SAGE questionnaire and the other five fielding a summary version. INDEPTH was collaborating with WHO-SAGE, with funding from the National Institute of Health (NIH).

The third presentation was made by Mark Collinson of the Agincourt DSS. Mark's presentation provided an update on work being carried out by the Migration and Urbanisation Working Group. He provided a conceptual framework highlighting the inter-relationship between migration and health. He reported that the monograph was at an advanced stage of production, and should be ready for publication by the end of the year. Individual chapters were currently under review.

A participant noted that DSS data were able to describe fairly well characteristics of people who migrated within the DSS areas, but not of those who migrated to cities. It was also noted that because there were few urban sites, it was difficult to adequately understand migration dynamics in urban areas. However, it was recognised that DSS data were helping to conceptualise new forms of migration that is, to understand the links between rural and urban areas due to cyclical migration.

The forth presentation was by Sanjay Juvekar of Vadu DSS in India on the development of a prototype data system for sharing data among participating sites. It stipulated a minimum data set and developed a standard unique data structure that would facilitate data sharing among sites. The presentation outlined the detailed architecture of the data system and also the protocol put in place for data requests as well as the procedures for obtaining permission to access the data.

The presenter then summarised the benefits of data access as follows: public money, professional responsibility, mark of scientific progress, fostering open scientific community, allowing for verification of the data, improving methods and measurements, encouraging multiple perspectives, protecting faulty data and increasing future funding opportunities.

However, he also pointed out the risks of uncontrolled data access as follows: poor quality data could be misleading, ownership concerns, sponsors' concerns, financial costs for data collection and access, risks to privacy and confidentiality and lack of incentives for data sharing

During discussion, it was pointed out that the procedure for obtaining permission to access data was too complicated and ought to be simplified. However, the presenter indicated that the protocol was such that it could respond to requests in real time. A participant questioned the rationale for the lengthy protocol for data requests if there was already commitment from each of the sites to participate in this process. Another participant noted that if there was agreement among the sites to participate in the data sharing initiative, then there was really no need for requests to go to the sites as they could be routed directly to the person responsible for handling the data warehouse.

## 2.3 Plenary 3 - Using DSS to monitor poverty dynamics

The following papers were presented:

- 1. Catastrophic burden on households? Out-of-pocket health expenditures in Vietnam. **Nguyen Thi Bich Thuan, et al., Filabavi.**
- 2. Economic mobility of migrants in Kanchanaburi DSS, Thailand. Aree Jampaklay, et al., Kanchanaburi.

- 3. Identifying poverty groups in Nairobi's slum settlements: a latent class analysis approach. Leontine Alkema, et al., Nairobi.
- 4. Monitoring poverty and vulnerability in an urban African setting: lessons from the Ouagadougou Demographic Surveillance System. **Jean-François Kobiané**, **Ouagadougou**.

#### Presentation 1 - Keynote address by Eliya Zulu

The presenter stressed that poverty was at the centre of the MDGs and efforts should be made at DSS sites to measure it. The presenter acknowledged the challenge in measuring poverty as it was difficult to agree on a standard definition. For example vulnerability vs. economic definitions – it was important to know what was being talked about; relative vs. absolute poverty; multidimensional – the Mark Montgomery schema of multi-dimensions of urban poverty, pyramid of poverty concepts. He noted that the most commonly used measure was consumption, however this had some limitations. To tackle this issue, APHRC organised a workshop in February 2007 in Nairobi. This workshop brought together experts working on poverty to discuss and develop tools to assess poverty dynamics better at the household level.

The presenter said, DSS sites could play a leading role in validating poverty definitions including poverty lines; providing evidence on how poverty dynamics influenced health; assessing transitions to and from poverty; assessing the protective effect of education; developing methodologies for identifying the poor. There was a strong need for partnerships with poverty experts in order to do justice to these areas.

**Question**: What is the punchline? – What method should DSS adopt?

**Answer**: The team is collecting data on income and expenditure and will see how good the data are. The jury is still out on what is the best measure since each indicator has strengths and weaknesses

Question: How are you thinking of moving forward with studies on poverty?

**Answer**: There is a need to create a working group on poverty – if enough interest is shown in the subject.

#### Presentation 2 – Nguyen Thi Bich Thuan, et al.

**Question**: There is the potential for circular causality – previous catastrophic health expenditure can lead to more poverty and therefore more susceptibility to another catastrophic health event.

**Answer**: This is the first study – it is true that those who pay more for health might be more prone to ill-health. More research is needed.

**Question:** Looking at expenditures – the relatively well-off tend to spend less. Is it because they don't fall sick or does it cost them less? Put the other way around: the poor may be sicker, and may therefore need to spend more. What drives it: the poverty or the ill-health?

**Answer**: Hospital costs might be the same for rich or poor, but poor people are caught in a poverty trap. More research is needed to tease out the answer.

#### Presentation 3 – Leontine Alkema, et al.

**Comment**: You are using a principle components analysis at each time point, which gives you a relative poverty measure at each time point. To arrive at a better measure of change you might need

an absolute measure at each time point, then you can compare a household's value with its previous value and judge whether it is going up or down (rather than comparing the later ranking with the previous rank.

Response: The author agreed with the comment and undertook to think about it.

Question: How far does the dataset go? Does it go far enough to measure change?

**Answer**: Five years of data are available and two data points. That should be enough for a first study.

#### Presentation 4 – Jean-François Kobiané

No particular comments or questions.

#### 2.4 Parallel Session 1- INDEPTH Network Activities 2

Professors Fred Binka and Don de Savigny presented the Phase IV proposal and Dr Hassan Mshinda gave a feedback on comments from The Bill and Melinda Gates Foundation following to the review of the proposal.

The meeting learned that the project was a consortium involving the following organisations: INDEPTH Network, the World Health Organization (WHO) Special Programme for Research and Training in Tropical Diseases (TDR), WHO Regional Office for Africa (AFRO), the London School of Hygiene and Tropical Medicine, the Centers for Disease Control (USA), the Swiss Tropical Institute, the School of Public Health, University of Legon (Ghana) and the Health Economics Unit of the University of Cape Town (South Africa). The objective of the project was to assess the safety and effectiveness of anti-malarial drugs on the African continent in response to the ongoing deployment of Artemisinin-based combination therapy (ACT) and other new drugs used to treat malaria, with a particular focus on safety, to inform policy better. Twenty DSS sites in sub-Saharan Africa covering about 1,500,000 inhabitants would be involved, with a plan of extension to sites in central Africa. Surveys would be conducted at community and health facility levels. Achievement of the project's objectives would also require linking DSS and health system data. This was a major challenge, given the weak interface between health systems and DSS. An international Task Team would be set up to address technical issues related to the implementation of the project if it was approved for funding.

The project had been submitted to The Bill and Melinda Gates Foundation (BMGF) and comments had been received. Overall, comments from the BMGF were encouraging. However the following concerns had also been raised:

- the project put more emphasis on safety than on effectiveness;
- there was a need to get the pharmaceutical industry to review the project;
- the number of sites involved might pose problems for the implementation of the project and management of funds;
- The budget should be scaled down;
- The independent scientific committee and the governance of the consortium needed to be restructured.

In the light of these comments, the number of sites had been reduced to fifteen and the budget cut down accordingly. The other comments were also being addressed.

#### Main points of the discussion

A major concern raised was whether the project was equipped enough to assess the effectiveness of anti-malarial drugs. Aiming to assess effectiveness would be more demanding as it would be important to know who received which drugs and who became ill. The project leaders pointed out that the issue had been discussed on several occasions and there was broad consensus that addressing safety would best fit within the DSS platform. Most of the drugs to be evaluated had already been approved and it was hoped that the study to be carried would help advise policy.

Household surveys and prospective cohort surveys at health facilities would be conducted. This would help address home management of malaria. In addition, alternative sources of drugs outside the formal health system would also be mapped out. One of the consortium partners, the CDC group, had good experience in that area which would be beneficial to the consortium. Therapeutic surveys would also be conducted at health facility and community level to monitor clinical outcome.

Whether data from the DSS would be representative of the picture of a whole country was another issue of concern. In addition, interference with the health system might lead to significant behaviour change at health facility level. It was also feared that restricting activities to the DSS area might not provide expected answers in understanding the health system.

In response to these concerns, it was recognised that the DSS might not be representative of what was going on in a country in terms of population and health facilities. However, if the project produced conclusive results, national malaria control programmes could be involved in order to expand the work to other areas in participating countries. While the possibility of behaviour change could not be ruled out, experience from previous studies suggested that this might not necessarily be the case. There was a real challenge in conducting studies involving health systems, but with the experience available within the consortium there was room for hope that the project's objectives were achievable.

Although malaria incidence was declining in some areas, it was necessary that the consortium comply with country-specific policy rather than promote the revision of existing policies such as IMCI in an attempt to minimise the number of unnecessary malaria treatments.

BMGF had only expressed concerns about the sustainability of provision of core funds to the sites, but not on the budget line for DSS support per site. In the revised proposal, it was worth noting that three years of core funding had been requested after the number of sites was reduced to fifteen as opposed to two years of core funding in the initial version of the proposal.

Finally it was suggested that the consortium should consider the role existing information education and communication (IEC) systems could play in this effort and possibly strengthen IEC within the DSS areas and beyond.

## 3 Day 2 - Tuesday, 04 September, 2007

## 3.1 Plenary Session 4 - Using DSS to monitor progress in education

The following papers were presented:

- 1. How achievable is universal primary education in Rural Ghana? Lessons from the Kintampo DSS. **Sulemana**, et al., **Kintampo**.
- 2. On enrolment and gender parity, pro-poor private schools for children from Nairobi's slum settlements have a point to make. **Epari Charles et al., Nairobi.**
- 3. The impact of orphanhood on progress in education in the urban informal settlements of Nairobi, Kenya. **Penny Holding et al., Nairobi.**
- 4. Assessing progress towards universal primary education in the Kassena-Nankana District of Ghana. **Cornelius Debpuur et al., Navrongo.**

# 3.2 Parallel Session 2 - Using DSS to monitor progress towards reduction in child mortality

This session comprised five presentations from different sites. However one of the presenters did not show up.

- 1- Descriptive analysis of verbal autopsy (VA) conducted on children under 12 in Western Kenya, 2002- 2005. **Lazarus O. Odeny et al., Kisumu.**
- 2- HIV, orphanhood and socio-economic well-being in rural Tanzania, Urasa. **Doris Mbata et al., Ifakara.**
- 3- Randomised trial of the effect on mortality, morbidity, and vitamin A Status of 50,000 IU vitamin A given with BCG vaccine to infants in Guinea-Bissau, West-Africa. **Christine Stabell Benn, et al., Bandim.**
- 4- Respiratory disease burden following severe respiratory syncytial virus infection among children admitted to Kilifi District Hospital. **Munywoki PK, et al., Kilifi.**
- 5- Beyond rural/urban: understanding contextual determinants of the dual burden of child malnutrition in Thailand. **Rebecca Firestone**, et al., **Kanchanaburi**.

The first presentation was an analysis of VA among children aged less than 12 years in Western Kenya. The study showed that mortality was high among the neonates and lowest among children aged 5 to 11 years. Overall, child mortality in Western Kenya had decreased, but deaths due to malaria had decreased significantly. The leading cause of death among the neonates was neonatal sepsis, with malaria being the leading cause among the post neonates and children aged 1 to 4 years.

The presentation raised several questions from the audience. Of importance was coding the main cause of death using VAs. It was noted that, there were observable differences in coding the main cause of death by different people, i.e. doctors and clinical officers. The presenter promised to look into this.

Another question was how to distinguish between malnutrition and HIV AIDS: the presenter noted the complexity of the changing main cause of death among children aged below 12 and especially in this era of HIV AIDS. One of the participants wanted to know if there were efforts to distinguish stillbirths from neonatal deaths. The presenter noted that stillbirths were excluded from the analysis,

this was made possible by using the INDEPTH /WHO guidelines for the VAs as well as the unique characteristic of DSS whereby pregnancies are followed from conception to birth making it easy to distinguish such deaths. A question that remained unanswered was why there was a notable decline in the number of neonatal deaths between 2003 and 2005.

The second presentation was on a randomised control trial investigating the effect of vitamin A supplementation (VAS) on mortality and morbidity of infants in Guinea-Bissau. This study revealed interesting findings that raised several questions from the audience. One of the interesting findings was that the effect of VAS varied according to age and seasonality whereby the effect of VAS on mortality was lower during the rainy season than during dry periods. The effect of VAS on mortality and morbidity was lower among girls than in boys. The audience was curious to know why there were variations in the effect of VAS due to seasonality. The discussant noted that there was no known biological explanation for this. The study also showed that the effect of VAS was felt above the age of four months. She noted that the effect of VAS at birth seemed to be modified by subsequent DPT vaccines leading to increased mortality among girls.

The third presentation was: Respiratory disease burden following severe respiratory syncytial virus infection admission among children admitted to Kilifi Hospital. This study showed that there was an increased risk of pneumonia following severe RVR compared to the no LRTI group. However, there was no notable difference between "LRTI with no RVR" and severe RVR. The discussant noted that the rate of readmission decreased with age. The study clearly showed how DSS could be integrated with hospital data in monitoring diseases in a community. The only concern about this study raised by the participants was the causal association of wheezing and RVR (which came first?). The presenter promised to explore the data further to determine the sequence.

The last presentation was based on the determinants of the dual burden of child malnutrition in Thailand. The presentation clearly showed that there were differentials in child growth not only for household wealth but also at community level, geographical accessibility of these communities and gender. Of importance was that household wealth persisted in all levels as a determinant of being either overweight or underweight. The concern was whether the same households were followed over the duration of the study and the effect of migration in this study. Despite migration data being available, it was not considered in the analysis. Secondly, there was concern about the influence of ethnicity on child malnutrition as different ethnic groups were known to have different practices and beliefs impacting on child health. The discussant acknowledged this. However, given Thailand's mixed ethnicity, the interrelationship with poverty was recognised as being complex which might make teasing it out cumbersome. She, however, promised to look into the issue to determine if ethnicity had any effect on child malnutrition. One participant noted that there was a need to investigate the association between lifestyle and place of residence (rural or urban residence) and check the interaction between SES and place of residence; however for this, follow up work would be necessary.

In conclusion, the audience followed attentively what the presenters had to say which made the session interesting and interactive. Each presenter acknowledged the importance of DSS in monitoring mortality to determine the extent to which countries were meeting the laid down Millennium Development Goals, particularly the reduction of child mortality.

# 3.3 Parallel Session 3 - Using DSS to monitor progress towards reduction in child mortality

- 1- Experiences from analysis of social autopsies on fatal acute febrile illness episodes in children in the Iganga/Mayuge DSS. **Karin Källander, Iganga**.
- 2- Spatial distribution and determinants of childhood mortality in rural Western Kenya 2002-2005. **Ombok et al., Kisumu.**
- 3- What can DSS contribute to monitoring MDGs: the use of indirect estimation for measuring infant and child mortality in the district area in Purworejo. Siswanto Wilapo, et al., Purworejo.
- 4- Is the Millennium Development Goal 4 in sight? The case of the Rufiji Sentinel District. Masanja Honorati. et al., Rufiji.
- 5- Diptheria-tetanus-pertussis (DTP) vaccine and child survival in low-income countries: Nine observations on the non-specific effects of DTP. Peter Aaby, et al., Bandim.

## 3.4 Plenary Session 5 - Using DSS to monitor progress toward improvement in maternal health

A keynote address was given by Prof. Will Stones, Aga Khan Hospital, Nairobi, Kenya. This was followed by three presentations:

- 1. Acceptability of evidence-based maternal-neonatal care practices in rural Uganda implications for programming. Peter Waiswa, et al., Iganga.
- 2. Burden and causes of maternal mortality in rural western Kenya, 2003-2005. **Peter Ofware, et al., Kisumu.**
- 3. What does access to maternal care mean among the urban poor? Factors associated with use of appropriate maternal health services in the slum settlements of Nairobi, Kenya. **Jean Christophe Fotso, et al., Nairobi.**

The first speaker on this theme was William Stones, who presented work from an obstetrician's point of view. He had tried to link maternal mortality with neonatal deaths. He observed that in countries where maternal mortality was high there were correspondingly high neonatal deaths. He stated that even though the rates were very high there were difficulties in capturing data on maternal mortality in DSS databases. He presented a three-delay model of situations leading to maternal mortality. These he named as:

- Delay in identifying pregnancy complications;
- Delay in seeking care on pregnancy complications;
- Delay in getting treatment at the facility level.

He tasked DSS sites with collecting data in these areas to help identify causes of maternal deaths .there. His presentation was basically about how to enrich data collection at DSS sites regarding maternal mortality, so not much discussion arose from it. However, participants noted the importance of the new dimension that DSS could bring to our understanding of maternal mortality in DSS sites.

The next presentation was by Peter Ofware and his group, who had examined **the magnitude and causes of maternal mortality in Western Kenya.** The authors noted that ante-natal clinic (ANC) attendance was very high in Kenya (about 90%), but about 80% of deliveries took place at home. About 43% of deaths occurred as a result of pregnancy related (direct causes).

During the discussion, participants noted that the authors had limited themselves to maternal mortality to the neglect of maternal morbidity which contributed to high maternal mortality in many countries. Participants also noted that data were estimated from the national mortality figures and that biases could be introduced by undereporting deaths arising from pregnancies. Discussants also thought that verbal autopsy could be used to look at community factors relating to maternal mortality. As such it would be important for DSS sites to adopt techniques of inquiring into the causes of maternal mortality at the community level, using the long established longitudinal data.

Discussants concluded that it would be inappropriate to compare verbal autopsy results with hospital post-mortem results as the two results were based on different criteria altogether.

Presenting the topic, Acceptability of evidence-based maternal-neonatal care practices in rural Uganda: implications for programming, Peter Waiswa and his colleagues noted that neonatal mortality was a particularly serious problem in rural Uganda. There were in excess of 56% neonatal deaths in rural Uganda compared with urban Uganda. However, research in Asia and South America had revealed that there were low cost interventions capable of reducing neonatal mortality to between 20% - 40%. The emphasis in Africa, however, had been to improve service delivery at the facility level. Recent government policy had been to implement these evidence-based maternal neonatal interventions in Uganda. The authors therefore sought to investigate the acceptability of this new policy initiative in Uganda so as to inform policy.

Discussants commended the authors' work but stressed that it would be useful for them to broaden the study by understanding what had so far been the normal practice in terms of neonatal care practices of women in rural Uganda.

The next presentation was by Jean-Christophe Fotso and his colleagues, entitled, "What does access to maternal care mean among the urban poor? Factors associated with use of appropriate maternal health services in the slum settlements of Nairobi, Kenya. Presenting from a background where maternal mortality is high, (1000 deaths per every 11000 births), coupled with poor service provision, the authors argued that since only unlicensed sub-standard clinics served the two slum areas and Government found it difficult to provide quality health care in the slum settlements, the unlicensed sub-standard clinics should be licensed and made to meet the minimum standards required to enable them provide quality services to slum dwellers. They had also discovered that uneducated women were more likely to seek health care from inappropriate health facilities.

During the discussion session, participants asked why only 2,000 women were considered for the study, and the response was that only 2000 women could be followed in the two study areas which were the only sites where data were available. Also at issue was the authors' failure to determine which women had delivered babies at proper facilities in order to control for the sub-standard facilities, before comparing the results with Kenya as a whole. However, the authors argued that the slum areas were unique and it would have been misleading to separate women delivering at better facilities from those delivering at sub-standard facilities.

## 3.5 Parallel Session 4 - Working Groups

#### 3.5.1 Adult Health and Aging Initiative

In total, 27 participants from 11 INDEPTH sites, Aga Khan University, Umea, the Wellcome Trust, and the SAC attended this session. See detailed list below.

#### Sites:

Agincourt, South Africa Matlab, Bangladesh Bandim, Guinea-Bissau
Navrongo, Ghana Watch, Bangladesh Ouagadougou, Burkina-Faso
Nairobi, Kenya Abhoy, Mirs, Kam, Nouna, Burkina-Faso
Vadu, India Bangladesh Ifakara, Tanzania

#### Others:

Aga Khan University Umeå Peter Smith – Wellcome Trust SAC: Tom Smith, Halima Mwenesi

#### Fieldwork experience

#### • SAGE – long

- 1. Navrongo interview and measurements took far too long.
- 2. Vadu unreliable, non-standardised equipment for measurements, e.g. Spirometer (needed valorisation). Focus on elderly very welcome. With experience, time of survey decreased to acceptable levels
- 3. Agincourt interview + measurements took three hours initially but reduced to two hours by the end, which was an acceptable length of time. Similar experience with spirometry problems as Vadu WHO knew about problems beforehand. Focus on elderly very welcome.

#### Short module

- 1. Agincourt very acceptable length. Focus on elderly very welcome (Vadu also).
- 2. Nairobi very difficult due to environment. 75% of older people still worked very hard to find them. Vignettes extremely difficult even fieldworkers could not follow that they were being asked to pretend that they were other people.
- 3. Matlab could not manage vignettes with the very elderly.

#### Future work

Analysis workshop:

- Planned for April/May 2008;
- Joint workshop of INDEPTH and WHO. Workshop structured to allow INDEPTH-only meeting for a couple of days; then WHO to join for cross-site analysis;
- Site-specific data cleaning should occur over next couple of months;
- Couple of months needed thereafter to create a cross-site dataset;
- Some basic analyses should be done in advance of workshop;
- Suggestion made for an INDEPTH publication possibly a journal supplement with papers from each site as well as a cross-site paper.

#### Update on progress

- Data collection complete in most sites; Vadu full SAGE complete and short module well under way;
- Data cleaning completed in Agincourt and Nairobi and Purworejo;
- Analysis very basic analyses in Agincourt; Nairobi further along with analysis.

#### Next steps

#### • Variables

To determine which DSS variables to add to adult health data, e.g. core data, special modules.

- O Core: DOB, gender, death, migration, education, occupation, employment, marital status, live births for women. Variables should be simplified to limit complexity. Most data needed should be broken down and new variables created.
- o **Special Modules:** GIS distance to health centre, Asian NCD data, reproductive health, physical and mental health (not available at all sites).

#### • Data needs

Finalise dataset;

Determine capacity needed to prepare dataset at each site;

Prepare data dictionary at each site;

Produce cross-site dataset ready for analysis workshop.

#### Suggestions for published output:

From the outset, it was necessary to consider the following: the core set of papers. What questions they were to answer? Who within each site should lead on papers? Plans for further exploration of cross-site data? The need to precede papers with a more theoretical paper on outline of analysis, hypotheses, etc. A sub-group could lead on this prior to the 2008 analysis workshop. Necessary to remember that there was only a 1-2 year time frame within which INDEPTH should publish, and then data had to be opened to wider scientific community (NIA/WHO requirement).

#### Suggestions for comparative analyses (Catherine Kyobutungi)

Descriptive paper comparing sites;

Within sites – having internal benchmark (e.g. median score) and see how individuals related to benchmark (similar to child growth). Could develop an African and an Asian benchmark – see how these two differed.

Question: Are there differences between African and Asian vignette experiences?

**Answer**: Can bring in other data – e.g. diseases in the elderly – and compare them across sites

#### **Questions for WHO:** Is there funding for analysis of bloodspots?

**Answer:** Vadu and Navrongo did discuss funding for 2008 workshop – although no funding earmarked for this, it will be found.

#### Asian Non Communicable Disease (NCD) group

Artificial divide based on geographic Asian focus. It was desirable that the adult health and aging and NCD monitoring groups come together.

NOTE: There is a Lancet editorial on preventing chronic disease

#### 3.5.2 Sexual and Reproductive Health - Eliya Zulu, APHRC

#### Background on previous meetings of the SRH Working Group

The convener, Eliya Zulu, presented a paper on the history of the SRH Working Group. At the 2006 AGM held in Durban, 28 INDEPTH sites completed a questionnaire to indicate SRH areas on which they were working and those interested in pursuing further work. During the 2006 AGM held in Ouagadougou, the Working Group members identified three areas of research focus: fertility trends and differentials; maternal health; and contraceptive use dynamics.

A committee was created to spearhead the activities of the Working Group and it was agreed that a few external people should be incorporated into the committee. It was decided that a first activity of the group should be to produce a monograph on fertility, with core chapters on fertility trends and differentials across all the sites, and site-specific chapters on related themes. It was agreed that the next step was to attract funding for a workshop to plan the monograph.

#### Progress since the last AGM

To date, funding to hold the fertility monograph workshop had not been secured, but Hewlett had expressed interest in funding INDEPTH to carry out ground-breaking research on SRH.

APHRC had received a small grant from The British Council for convening a workshop on population dynamics and well-being. This workshop was held in March 2007, involving 6 DSS sites (Nairobi, Kilifi, Navrongo, Kisesa, and Ifakara), and the Population Studies Research Institute of University of Nairobi's DSS in Rusinga (Kenya). This workshop aimed to carry out joint analyses, but it was discovered that SRH data varied considerably between sites. It was therefore decided that it would make sense for a few of the sites to develop methods which could then be shared with other sites. The main focus of the analyses would focus on birth intervals and their effect on fertility and child survival. At the same workshop, maternal health and adolescent SRH were identified as subjects in which sites were interested.

#### Participants' ideas for future work

Participants spoke about their current interests and ideas for the Working Group:

- Maternal and child health, neonatal mortality (Iganja);
- Research collaboration between population-based and clinical-based institutions (Aga Khan Hospital);
- Comparing data collected at the community level with health facility data (Kwale);
- Public health and RH (Navrongo, University of Witwatersrand);
- Two sites were working on trials/impact assessments of Adolescent SRH interventions (Mwanza, Navrongo);
- STI-prevention project (Zimbabwe, LSHTM);
- Population growth despite HIV infection and mortality rates (Zimbabwe, LSHTM);
- Relationships between poverty, migration and SRH issues (APHRC);
- Sexuality (Witwatersrand);
- Question of how to use existing SRH data collected;
- Interactions between RH and poverty reduction (directions of causality) (HSPH, Harvard);

- Interactions between RH and HIV (HSPH, Harvard);
- Adolescent orphans socio-economic factors and RH.

#### The Fertility Monograph

Participants argued that there were good reasons for prioritising the fertility monograph – because data were available and because it could make a considerable contribution to knowledge on fertility trends during the past ten years. Participants also argued that the INDEPTH sites were collecting data on other important SRH issues, so it was important that the book address these issues as well. It was suggested that the interface between S and RH would be of particular interest. It was agreed that the site-specific chapters would be substantive and would address these issues. Authors of site-specific chapters would be encouraged to combine analysis of qualitative and quantitative data.

Participants acknowledged that progress with the monograph had been slow, so there was a need to identify ways to ensure that it was quickly taken forward. It was suggested that a workshop be organised. Each site would prepare data in advance and the key researchers working on SRH would attend.

To move the work forward, it was agreed that a dedicated group should be formed to coordinate the data analysis for the monograph among interested sites. The following were suggested as possible members of the committee:

- Makandwe Nyirenda and William Muhwava of Africa Centre and Cornelius Debpuur of Navrongo were nominated for this committee;
- A demographer from Asia needed to be identified;
- APHRC would identify someone to convene the committee;
- Rosalia Sciortino of Mahidol University was potentially willing to be an external adviser if the monograph effectively addressed SRH issues.

It was agreed that the team should move fast to get the work under way and liaise with the Secretariat to mobilise funds to facilitate it.

It was noted that junior scholars should be closely involved in the production of the monograph so they could gain experience in this sort of work since a number of them were interested in SRH. It was agreed, therefore, that sites should ensure that they included the junior scientists in their scientific teams to work on this, and that the junior scientists should be directly copied communication on the activity so they could provide their own insights.

#### The need for a broader SRH Agenda

The participants noted that the set of topics of focus agreed on at the Ouagadougou meeting represented a very narrow view of SRH as they mostly focused on demographic issues. It was agreed that a committee should be set up to define a broader SRH agenda for the Network to pursue and sell to various donors. This should be done while the technical team mentioned above was working on the fertility monograph.

It was agreed that the convener of the group should liaise with the INDEPTH Network Secretariat to put together a team to define the SRH research agenda and involve a wider group of individual scientists interested in the topic.

It was agreed that further comments and perspectives on the issues discussed at the meeting should be sent to Joanna Crichton (<u>icrichton@aphrc.org</u>) and Eliya Zulu (ezulu@aphrc.org)

#### 3.5.3 Mental Health

Attending were representatives from Kanchanaburi (Sureeporn Punpuing), Kilifi (Charles Newton), Butajira (Ed Fottrell, Umeå), Ballabgarh (Anand Kaisnan), and Rufiji (me). Penny Holding from the African Mental Health Foundation wished to attend but could not. She, however, wished to remain involved. The discussions led to the following conclusions/action items:

- Hard and electronic copies of the new Lancet series on Mental Health to be obtained and distributed to the Working Group members listed;
- The new INDEPTH Bibliography to be examined to identify prior INDEPTH work on Mental Health related topics and share the information. (Responsible, Amanda Brosius)
- A list of grey literature to be made available for examination by Dr. Ngugi, currently working on the Epilepsy Project. at Kilifi
- Ballarbgah, Butajira, and Kanchanaburi had been using mental health survey instruments in their DSSs. It would be a good idea to canvass the whole network for such instruments (if that had not already been done), and make them available through the on-line Resource Kit on the INDEPTH Website. If this idea had merit, Dr. Osman Sankoh should be asked to make the request. For the moment existing instruments could be posted on the INDEPTH web page.
- Charles informed and updated the group on the Kilifi INDEPTH multi-site proposal (Kilifi, Rufiji/Ulanga, Iganga, Kintampo, and Agincourt) for prevalence, causes and outcomes of epilepsy in sub-Saharan Africa, which had been submitted to The Wellcome Trust: and was awaiting review.

## 4 Day 3, Wednesday, 05 September

## 4.1 Plenary Session - INDEPTH Network General Assembly

The Board Chair, Dr Hassan Mshinda, opened the 7th AGM - the general assembly of the Network attended by full members, associate members and other stakeholders of INDEPTH, including the Scientific Advisory Committee (SAC) and funder colleagues. He welcomed all site leaders, the SAC, funder colleagues, DSS scientists and all other participants to the session. He then invited Prof. Fred Binka, the outgoing Executive Director of INDEPTH, to present his Annual Report.

(See **Prof. Binka's power point presentation for details** -- this is based on the annual report 2006. However, since this was his last presentation, he gave an overview of activities in 2007 up to the AGM in Nairobi)

#### Discussion

After the Executive Director's presentation, there was a question and answer session.

#### On overheads for INDEPTH

Unlike our counterparts in the North who receive up to 40% overheads from funders, the Secretariat had still not been fortunate enough to receive generous overheads. The Secretariat considered itself lucky if a funder approved 15% overheads.

#### • Geographical distribution of membership

Since sites did not pay for membership, there had not been a drive to expand membership as that would simply drain the already limited resources of the Network. Even with the current members, there was a need to improve on the quality of membership. Some members only showed up at AGMs and contributed little to network activities. However, an open-door policy for membership would be maintained.

#### Subscription fees and site contribution to INDEPTH

Some participants suggested a token subscription by sites to demonstrate their commitment to the Network. The Secretariat should pay for scientists from the sites to present papers at the AGM while sites ought to cover the costs of the attendance of site leaders to the AGM. This issue should be further discussed by the site leaders.

#### • Board election

There were only two nominees for the three vacant positions on the Board. Hence the nomination process was opened up again and the election postponed to the next day. After the close of nominations, four site leaders were nominated. The following three were eventually elected to the Board:

- Dr. Siddhi Hirve (Vadu DSS, India re-elected)
- Prof. Peter Aaby (Bandim DSS, Guinea-Bissau)
- Dr Thomas Smith (Kilifi DSS, Kenya).

The continuing members were:

- Dr. Seth Owusu-Agyei
- Dr. Sureeporn Punpuing

- Dr. Abdur Razzaque
- Dr. Cheikh Mbacke
- Dr. Regina Rabinovich

#### Board composition

The Board Chair informed the AGM of advice received from the outgoing Executive Director drawn from an expert committee report. The expert committee had been put together by the outgoing Executive Director to advise the Network on how to take advantage of emerging opportunities. Given the growth of the Network, the report called for an adjustment to the Board's current composition to accommodate other stakeholders such as ministers of health, donors, etc. A resolution was sought to give the Board permission to expand its membership, but the AGM agreed that a broader discussion with site leaders was necessary. Some members cautioned against having donors on the Board saying this might be counterproductive. They said there was a need to understand the dynamics of donor participation on boards such as INDEPTH's.

#### • Prof. Fred Binka, outgoing Executive Director - exceptional service applauded

The Board Chair thanked the outgoing Executive Director for his exceptional service and invaluable contributions to the success and growth of the INDEPTH Network. He signalled that Fred Binka was not leaving INDEPTH for good since he would remain as the Project Manager of the Malaria Clinical Trials Alliance (MCTA) - an INDEPTH project.

#### • Dr. Osman Sankoh introduced as incoming Executive Director

The Board Chair introduced Dr. Osman Sankoh as the new Executive Director effective 1 October 2007. Dr. Sankoh was appointed Deputy Executive Director in May 2006 after serving INDEPTH from July 2002 as the Network's Communications and External Relations Manager. The Board Chair said he and the Board were very confident that they had made the right choice and wished him every success.

#### Closing remarks by the outgoing Board Chair

In his closing remarks, the Board Chair thanked the Network and Board colleagues for the support he received during his tenure. INDEPTH had been successful but there were still many challenges to face. The Network needed a stronger Board which could effectively handle a wider INDEPTH portfolio. The Board Chair expressed a desire to expand INDEPTH's impact on policy and practice and to be able to show through the Network's collective work, what it meant to have 37 member sites. He said that data sharing was crucial and that it was time that the mechanisms to do this better were sorted out. The Board Chair also stressed the need to maintain strategic partnerships/collaborations with groups such as the Health Metrics Network.

#### Young scientists meeting, facilitated by Dr David Ross

Dr. David Ross first talked to young scientists about how to turn an idea into a research project, and then about how to turn study results into publications. He highlighted the dos and don'ts that apply in formulating research questions and ideas. He then went on to give several examples of how to formulate research questions, and how to turn these questions into research projects. In addition, he briefed young scientists on publication strategies, which included: sponsor requirements and main paper development. He also talked about the need to allow cross-referencing in subsequent papers, by putting the study on the map right away, and the need to allocate responsibilities and deadlines to all involved in the publication. Furthermore, Dr. Ross highlighted the issues to consider when

choosing a journal and instructions authors must follow. Finally, he discussed extensively with young scientists the general structure of a research paper and indicated the order in which the various sections should be written, touching on; Title, Authorship, Abstract/Summary, Introduction/Background, Materials & Methods, Results, Discussions, Acknowledgements, References, Tables and Figures.

## 4.2 Parallel Session 5 -Site leaders and young scientists session

About thirty site leaders were present. The Chair expressed disappointment that a form which had been sent out to site leaders prior to the meeting had been returned by only two sites. This had made preparing an agenda for the meeting a challenge. He therefore picked up issues that arose from the general assembly held earlier in the day to be tabled for discussion as follows:

- 1. Individual assessment of site contributions to network activities such as,
  - a. leadership programme at Witwatersrand University;
  - b. Membership of working groups;
  - c. Initiation of working groups;
  - d. Contribution of data to monographs, etc.,;
  - e. How sites could contribute to supporting the Network;
- 2. How sites could contribute to core network activities (AGM, etc.) and scientific work and programmes;
- 3. How the Network could support sites more;
- 4. How sites could contribute to supporting the AGM and looking for funds to support the AGM;
- 5. Governance
  - a. Tenure of the Board;
  - b. The Board's composition and distribution;
  - c. Nomination of site leaders to the Board;
  - d. How to establish a strong and dynamic Board;
  - e. In Alex's view, the site leaders meeting was the key activity of the AGM and he wondered whether a 2- hour session at every AGM was enough for the sites to deal with issues concerning the Network and the Secretariat, review progress and discuss the way forward.

Site leaders were then invited to make general comments and a number of issues were raised:

- Site leaders were out of touch with the Board and Secretariat except at the AGM. It was important that the Secretariat and the Board have greater interaction with site leaders during the course of the year, through circulation of minutes of board meetings and other documentation if possible. This would draw site leaders closer to the Board and the Secretariat;
- The issue of language had to be dealt with in the interest of people from Lusophone countries;
- The need for the sites to be more engaged in issues to do with morbidity and child survival, access to vitamins and bed nets instead of simply keeping track of migrations;
- There was a need to have a more structured site leaders' meeting with an agenda and with minutes of previous meetings which should be read and adopted to allow for follow-up of issues raised in previous years.

• Site leaders needed to be more responsive to requests for information so as to enable the Secretariat to work more effectively.

The group then went on to discuss the issues raised in detail:

## How can our sites support the Network throughout the year, and not just at AGMs?

A number of suggestions were made:

- Sites should contribute more towards strengthening the working groups and put in more competitive proposals to be funded. The Secretariat should not be solely responsible for setting up working groups. Sites could take the initiative in that regard. The group agreed that there might be a number of reasons why the working groups did not seem to be moving forward and it was important for the Secretariat to find out the reasons and address any problems identified. Possible reasons could be lack of funding, lack of staff or lack of interest in the areas for which the working groups were advertised. The Secretariat should assess the status of working groups before the AGM and include a slot in the programme so they could meet.
- The Secretariat needed to compile a list of core staff from the sites and their areas of expertise, and circulate it among site leaders. This would make it easier to know whom to contact in times of need.
- To be active members of the Network, sites should be willing to submit to the Secretariat some minimum information about their establishments. This minimum information needed to be agreed upon with the site leaders. There was also a need for site leaders to be more responsive to requests for data to enable the Secretariat to compile information on the sites before AGMs.
- Sites should be willing to contribute staff time to the Secretariat to support the work of the Network, and this must be accompanied by feedback from the Secretariat on the outcome of the support given.
- Involvement in other network activities other than the AGM was important, but sites might not be aware of some of these "other activities". It might be necessary for the Executive Director to provide on a regular basis, information on sites that had participated in non-AGM activities, determine the factors that led to their participation, and identify reasons why others had not taken part.
- Sites needed to know the strategic plan of the Network and indicate how they could contribute to it. If sites had developed their own strategic plans there was a need for such plans and information on progress made on them to be passed on to the Secretariat.
- Site leaders in addition to thinking and planning for their sites should think about the Network and advertise it in any way possible, and it was important for the Network to be made aware of such publicity. Sites could be advertised and marketed through:
  - o Publications;
  - O Submitting to the Secretariat regular profiles of the site and how much it costs to run it;
  - o Submitting to the Secretariat data on particular themes for production of monographs.

It was possible that donors were reluctant to support the Network because there seemed to be no deliverables.

#### Submission of data to the Secretariat

The group spent quite some time discussing possible reasons why sites were not submitting data to the Secretariat, and arrived at possible solutions. That the secretariat should:

• indicate to sites the minimum required for contributing data;

- send to sites ahead of schedule the information that needed to be provided before an AGM;
- cancel the Network membership of sites that did not submit their data sets.
- check from the population reference bureau site for the indicators that could be used as a template for data contribution.

#### How can sites support the AGM?

In view of the fact that the Secretariat did not have extra support for organising the AGM, there was a discussion on how sites could be of assistance in this regard. Site leaders pointed out that everyone belonged to other networks, associations and partnerships, paid dues and fees to stay on those groups, and paid to attend their annual meetings because they considered them extremely important. The group agreed that if sites also saw the Network as important, they should be willing to contribute a small amount as annual fees towards the AGM. However, in attempting to get sites more committed to the Network, care should be taken not to exclude young sites that were not financially sound.

Other suggestions were made in relation to this issue. They included the following:

- The Secretariat should pay air fares and sites pay for other expenses;
- The sites should pay for air fares and the Secretariat for other expenses;
- To be a member of the Network subscription fees should be paid;
- Holding the General Meeting biennially instead of annually;
- Reducing the number of subject areas and days for the meeting.

The group agreed that since the Network was still young and its aim was networking as well as promoting science, the annual meetings should continue. However, for the next AGM, interested sites should pay for their transport to the meeting and the Secretariat would pay for all other expenses.

The theme areas should be left broad to encourage as many sites as possible to attend the AGM.

Sites were also asked to indicate the amount of money they were willing to contribute to the Network as membership fees.

#### Governance

As a result of issues that arose during the General Assembly, the Chair felt there was a need to discuss issues of governance. The three key areas to be discussed were:

- 1. Election of the Chair and the number of years the Chair of the Board should to serve;
- 2. The composition of the Board;
- **3.** The role of the site leaders in nominating members of the Board, and members of the SAC. How site leaders should work with the Board on the nomination of members?

The Chair of the Board started the discussion by giving site leaders a briefing on its status. He indicated that the Board, and the administrative, organisational and managerial instruments needed to be stronger. He cautioned that funding agencies assessed the board of any organisation before deciding to put their money into supporting it. He was concerned that due to the current composition of the Board, personal agenda could adversely affect the Board and the Network.

The Chair's presentation drew many concerns from site leaders and several issues were raised:

- How much influence did the Chair have over the Board?
- What did it take to be a good Board member, etc., etc.?
- What did the constitution have to say about all these issues?

The group commended the Chair for being honest and bold enough to have raised the issues concerning the Board. It was agreed that as institutions grew there were bound to be problems and that more often that not, there was hardly any reflection of the past. It was decided that as the INDEPTH Network was becoming better established there was a need for sustained improvement in its own interest and in the interest of its supporters. It was important to recognise that INDEPTH was growing and needed to face the challenges that went with growth. It was also agreed that raising these issues was healthy for moving forward as a network and since the Board sought the interest of the Network; the group should make sure internal issues were properly addressed so that people outside the Network would continue to be interested in it. As there was so much uncertainty about the Network's constitution and site leaders had little knowledge about it, the Secretariat and the Board would be given the mandate to re-examine the constitution and present a new or amended version of it at the next AGM.

On the issue of nominations to the Board, the group agreed that in 2007 the procedures had been inadequate and expressed the view that for subsequent AGMs,

- The advert for nominations should be published earlier than it had been in 2007;
- People who wished to be nominated should submit their CVs as part of the process so that site leaders could assess the nominees properly;
- The group should consider having other influential people on the Board in addition to site leaders.

## 4.3 Plenary Session 7 - DSS and the HIV/AIDS epidemic

The following papers were presented:

- 1. INDEPTH work on ART roll out. Nyovani Madise, Nairobi DSS
- 2. Finding the best question for measuring AIDS mortality using verbal autopsy: a validation study in Kisesa, Tanzania and Manicaland, Zimbabwe. Ben Lopman, Centre for Infections, Health Protection Agency, London.
- 3. Prevalence among adults in two informal urban settlements of Nairobi, Kenya. Nyovani Madise, Nairobi DSS.
- **4.** Determinants of condom use among young adults 15-24 years in the Africa Centre Demographic Surveillance Area in KwaZuluNatal, South Africa, 2005. **Natsayi Chimbindi.**

#### Presentation 1 by Nyovani Madise

Question: How the sites involved in the proposed research plan were chosen.

**Answer:** She said that 12 DSS sites had initially expressed interest in the collaboration. However, not all showed commitment towards these plans. Some were dropped as they were not responding to the requests put to them. Three sites had received a grant to run similar activities and therefore were also dropped from these plans. That was why only five sites remained in the collaboration.

#### Presentation 2 by Ben Lopman

He presented a computer algorithm that included nine symptoms/signs developed using two longitudinal studies to investigate the most sensitive and specific set of questions to ascertain HIV/AIDS related mortality. The algorithm had been tested for consistency in both time and space.

**Question:** The presenter was asked whether they tried combining the symptoms instead of adding them one at a time as this would help indicate significant clustering for AIDS/not AIDS deaths. This would lead to probabilities being used that an individual most likely died of AIDS.

**Answer**: He advanced the main reason why the study was carried out, saying that the investigators wanted something which would be as simple as possible and easy to use at each site. When they tried out combinations they did not find any which performed better.

**Question**: He was asked whether they investigated how this algorithm performed with HIV/AIDS morbidity.

**Answer**: He said that there was a problem with morbidity measurements in the era of ART and that this suggestion would require MRR to estimate HIV prevalence. With ART much had changed, including the clinical spectrum that a researcher could use.

**Question:** He was asked to elaborate on the Gold Standard used.

**Answer**: He emphasised that validation mechanisms in the era of ART were widely available and suggested a clinical diagnosis on a subset of the subjects involved in this study.

#### Presentation 3 by Nyovani Madise

The presenter explained that this was preliminary work. She explained how the pilot was done, the number of samples and worked on, plus the numbers enrolled during the main study. She said that such work was feasible but challenging, especially finding the people identified for the study.

**Question:** Which test kits were used?, Were results availed to the people and whether treatment was provided?. If the results were not availed to the people had the investigators considered the ethical implications of this?

Answer: The investigators used Dry Blood samples (DBS) but did not routinely give participants their results. People who wanted to know their results filled in free vouchers which they presented at collaborating VCT centres in order to receive counselling and testing services if necessary. As for ethical considerations, since the results were aggregated at the community level researchers were not obliged to provide individual results. They mobilised and educated the community about this study and helped increase the requests for VCT at the official centres.

#### Presentation 4 by Natsayi Chimbindi.

The presenter is an MSc Student in epidemiology sponsored by INDEPTH network. She had investigated condom use determinants and patterns amongst those aged 15-24 years in 2005. This was secondary data analysis. There was no information on knowledge of HIV results in the study population.

**Question**: Did you consider other methods of contraceptive use amongst married women as a reason for failure to use condoms?

**Answer**: She described her study population with the majority (>92%) being unmarried. She also did not consider other contraceptive use as she found an interaction with condom use.

**Question:** The finding of high condom use among males raised the question whether these were men with same sex preferences or with partner(s) living either outside of the DSS area.

**Answer**: She confirmed that a partner living outside of the DSS area was associated with greater chances of using condoms. However, she had no confirmatory data as to whether partners lived outside of the DSS.

**Question:** She was asked whether those who used condoms mostly used them with high risk or low risk partners.

**Answer**: She had not considered this during this analysis but would work on it.

#### 4.4 Parallel Session 6

The following session took place:

- 1. Malaria Clinical Trials Alliance (MCTA);
- 2. Working group: Migration and Urbanisation;
- 3. INDEPTH Work on ART roll out;
- 4. DSS University collaboration roundtable.

Only the report from the MCTA group was submitted

### 4.4.1 Malaria Clinical Trials Alliance (MCTA)

This session was led by Dr. Bernhards Ogutu (MCTA/INDEPTH). He gave a presentation on Capacity building for malaria drug and vaccine trials in Africa.

An update on activities of the MCTA/INDEPTH project was given and included the following:

#### Sites for malaria vaccine trials in progress

- 1. Kintampo Health Research Centre, Ghana.
- 2. School of Medical Science/Kumasi Centre for Collaborative Research, Kumasi, Ghana.
- 3. Tanga Research Centre, NIMR, Tanzania.

#### Sites for malaria vaccine and drug trials

- 4. Bagamoyo Research Unit, Tanzania.
- 5. Albert Schweitzer Hospital, Lambarene, Gabon.
- 6. KEMRI/Wellcome Trust Unit, Kilifi, Kenya.
- 7. Manhica Health Research Centre, Mozambique.

#### Sites for malaria drug trials

- 8. College of Medicine, Ibadan, Nigeria.
- 9. MRC Labs, The Gambia.
- 10. Malaria Project, Ndirande, Malawi.
- 11. QE Central Hospital, Blantyre, Malawi.
- 12. State Specialist Hospital, Maiduguri, Nigeria.
- 13. Department of Parasitology, Faculty of Medicine (UCAD), Dakar, Senegal.

#### New sites that joined the MCTA network in 2007 for the RTS'S vaccine trial

14. Nanoro, Burkina Faso.

- 15. Kisumu, Kenya.
- 16. Lilongwe, Malawi.

#### MCTA's key activities included

- site audits
  - To gather detailed information on the sites;
  - To identify site needs.

#### Guiding Infrastructural development

- Refurbishment of Labs;
- Refurbishment of clinical facilities;
- Provision of new equipment to meet current requirements for regulatory purposes.
- Networking
- IT support
- Training
  - Malaria diagnosis-Microscopy;
  - Good clinical practices;
  - Good clinical laboratory practice;
  - Ethics;
  - Data management;
  - Training of finance managers;
  - Short-term attachments to sites with more expertise in specific areas;
  - Accreditation for CRC/CRA/CTI/CPI;
  - Leadership development.

#### MCTA in collaboration with AMANET had conducted GCP workshops

- 3 in 2006: Lambarene, Bagamoyo and Kilifi;
- Maputo July, 2007;
- Next GCP training in November, 2007 in Dakar.

#### • GCP certification course

Nairobi in May, 2007 (in collaboration with ACRP).

#### • Microscopy training (3 week courses)

- First training course in Kisumu, November, 2006;
- Second training course in April, 2007 in Kusimu;
- Next training course in October, 2007 in Kintampo, Ghana;
- A quality assurance system to be put in place for sites to exchange slides.

#### • Financial support

- Financial support for the upgrading of clinical trial facilities. Funds allocated to sites in 2006 to upgrade facilities for clinical trials: \$1,351,195.
- Funds allocated to sites in 2007: \$863,828.
- Requests from Kilifi, Bagamoyo were being reviewed. Kumasi, Lambarene & Manhica sites were still working on their budget for 2007.

#### Long term sustainability of research capacity at the sites

#### • General training

- 11 sites participated in a workshop to develop 5-10 year strategic plans;

- 5 Sites submitted a draft strategic plan;
- Submitted strategic plans had been reviewed and comments sent back to sites.

## Research capacity assessment at member sites

- 12 of 13 sites were visited in 2006;
- 7 sites visited in 2007.

#### • Mentorship programme

- MCTA drafted a document defining mentor's role;
- Mentors had been linked up with sites to assist with research capacity development;
- MCTA was looking forward to receiving feedback from the sites.

## • Facilitation of media interaction with scientists to improve reporting on malaria and site profile

- Media training to improve interaction between researchers and media;
- Support the formation of AMMREN in November 2006;
- Media expert visited 4 sites to hold discussions with scientists and local media and improve interaction between scientists and the media;
- MCTA supported a media workshop in Mombasa and participation in malaria day in Kilifi;
- MCTA to award \$10,000 for media relations;
- A communications expert had been contracted to work on MCTA's image.

#### Linkages/partnership

- MCTA had established linkages with Sanofi, Pfizer and GSK.
- MCTA's main partners were MVI, MMV, AMANET, EDCTP, and ACRP.

#### Official Meetings attended by MCTA.

MCTA Board paid a courtesy call on His Excellency, the President of Ghana and the Prime Minister of Tanzania.

#### Summary

- The implementation of MCTA's short- and long-term capacity building activities was satisfactory;
- Up to 7 sites now had the potential to run clinical trials in compliance with international standards;
- The challenge was now to bring a few more sites to a similar level and sustain the momentum;
- Additional resources would be required to effectively support the long-term sustainability of research capacity at the sites.

#### Way forward for MCTA.

- Development of the second phase of MCTA for long-term sustainability of research capacity at the sites and proposal in preparation by the MCTA Secretariat;
- Preparation of a publication on MCTA experience in research capacity building in clinical trials.

#### **Comments**

• Pathway or stages to be gone through before obtaining ethical clearance or any regulatory issues should be documented by MCTA Secretariat. This would enable funders to have an

- idea about timelines for a protocol to be approved by ethic committees and other regulatory bodies.
- Capacity of each site (infrastructure and personnel) must be made readily available at MCTA Secretariat and must be updated regularly. This would determine the kind of research each site could undertake.
- MCTA Secretariat to have an expert readily available with information in order to advise funders/sponsors where to go when they were ready with a product to test or any research work to be carried out
- MCTA Secretariat should always have information on the current trials being carried out by the sites so as to avoid competition for research participants and research personnel.
- Transparency must be the hallmark of all the sites. If they could not deliver they had to be honest about it.
- MCTA should focus not only on malaria but also on other diseases of public health importance such as HIV/AIDS and TB, especially in Eastern and Southern African countries where prevalence of malaria appeared to be decreasing.
- The issue of sustainability of sites was to be considered crucial. Sites should rather be developed to become clinical research sites and not necessarily malaria trial sites. This would equip them to have a broader base and to carry out any research activity rather than wait for another malaria product to be tested when they finished with one. It would also be very helpful if sites could pick up studies other than malaria-related ones.
- Sites should be encouraged to collaborate with universities since clinical research sites could be excellent platforms for learning.
- DSS must not be a pre-requisite for site selection because what was crucial in a drug trial was the ability to deliver, though DSS was an advantage. Mechanisms needed to work out how the follow-ups could be in place at sites with no DSS.
- Training in financial management for the sites would be a good thing since a lot of funds for research work were being managed from outside.
- Linking up of data sets from various sites was also a brilliant idea which the INDEPTH Network should pursue.
- Training programmes should be open to all DSS sites and not necessarily MCTA sites.
- The issue of correct diagnosis of malaria and its differentials was very important in clinical trials. In view of this; all MCTA sites were going to be equipped with x-ray machines. This would help with the diagnosis of some of the differentials of malaria, especially in children. X-ray readings would be sent to experts to read and interpret.

#### Challenges

- Sustainability of sites to conduct GCP-compliant clinical research at the end of a clinical trial to prevent staff redundancy.
- Clinical research sites to work with the policy-makers so that their findings could inform and transform policy.
- Characterisation and standardisation of all clinical research sites especially the clinical component to standardise diagnosis so that data could be matched and results compared.
- Establishment of QA system in Africa to keep costs down.

## 5 Day 4, Thursday, 06 September

## 5.1 Plenary Session 8 - Using DSS to monitor malaria control programmes

The following papers were presented:

- 1. The role of demographic surveillance systems in monitoring the burden of malaria and other important diseases: an example from Kilifi. Evasius Bauni et al, Kilifi.
- 2. Seasonal molecular characterizations of an asymptomatic cohort in a malaria endemic district of Ghana: Utilization of the Kintampo DSS. Akua Budu Agyeman et al., Kintampo.
- 3. Assessing the risk of self-diagnosed malaria in urban informal settlements of Nairobi. Yazoumé Ye et al., Nairobi
- **4.** Distribution of bed nets in Rusinga and Gembe West locations of Suba District. Demographic Surveillance System (DSS), Suba District. **Mohamed Karama et al., Kisumu.**

#### Presentation by Thomas Smith - Keynote address

A keynote presentation was given by Tom Smith from The Swiss Tropical Institute on 'the role of demographic surveillance systems in monitoring the burden of malaria and other important diseases'. He stressed that DSS was relevant for monitoring three of the MDGs related to malaria. DSS could also help address epidemiological studies, study effectiveness of interventions and monitor progress on mortality, intervention coverage in several countries across Africa, studies of effectiveness of interventions, such as the long term impact of nets on child mortality in Ghana and Burkina Faso, the MCTA project which involved DSS sites, the INDEPTH phase IV study aimed at assessing the safety and effectiveness of anti-malarial drugs to illustrate how DSS could effectively support the monitoring of malaria control activities. With the possibility of integrating verbal autopsy to DSS activities, DSS represented a real potential for monitoring trends in mortality in general and malaria mortality in particular as compared with Demographic Health Surveys (DHS).

#### Discussion

VAs coding had been a major problem across sites so there was a need for new approaches to improve the coding of VAs. In response to this suggestion, the presenter informed the group that INDEPTH was working with WHO to standardise VA coding, but this would not solve all problems associated with VAs such as sensitivity and specificity.

The presentation clearly showed how useful DSS was to sites in monitoring malaria control activities and described what needed to be improved. However, it would have been helpful if the presenter had come up with suggestions on new areas that sites could possibly address.

#### Presentation by Evasius Bauni et al.

The second presentation was given by Evasius Bauni (Kilifi, Kenya) on "the role of integrated demographic and diseases surveillance systems in monitoring the burden of malaria and other important diseases: example of Kilifi". In their approach, DSS, laboratory and clinical data were linked to determine the main causes of death in children under 5 and mortality trends between 2002 and 2006. Results indicated that malaria was the leading cause of death in 2002 and 2003, but moved from that position to rank third between 2004 and 2006. Estimates in 2006 showed that malaria mortality rate was 2/1000 child years as compared to 4/1000 child years in 2002. This decline in malaria mortality was likely to be associated with the implementation of malaria control activities in the area. The study also revealed that 57% of deaths in children under 5 occurred at home while only

35% of deaths happened at the Kilifi Hospital, suggesting that there was still much to be done to improve health seeking behaviour and access to health care in developing countries.

#### Discussion

It was pointed out that the results might be biased as only deaths that occurred at the Kilifi Hospital (35% of all deaths) were diagnosed for cause-specific mortality. For future similar studies, there was a need to use the VA technique to determine cause of death at community level.

Data on the proportion of confirmed malaria cases at the clinic and the level of malaria transmission intensity would have been useful for the interpretation of the study results. In response, Dr Evasius Bauni explained that all children enrolled in the study had had a laboratory and clinical diagnosis of malaria. As for the malaria transmission intensity, there had been a dramatic decline in recent years.

#### Presentation by Akua Budu Agyeman et al.

The third presentation by Akua Budu Agyeman, et al., addressed the following theme: "Seasonal characterizations of an asymptomatic cohort in a malaria endemic district of Ghana: Utilisation of the Kintampo DSS.

The authors used the Kintampo DSS data to randomly select 600 asymptomatic individuals aged 3 weeks to 78 years to study *Plasmodium falciparum* polymorphism as part of site description for a future vaccine trial. Multiplicity of infection (MOI) of MSP2 was determined monthly over one year using PCR. MOI was higher in children under 5 than in individuals aged 5-78 years (7 versus 3) between January and April, with a peak between March-April. The dominant strain in the areas was IC/3D7. MOI was much lower in both groups during the rest of the year. This data would be useful in monitoring the diversity of *P falciparum* after the introduction of vaccine and drug trials.

#### Discussion:

MOI of 7 seemed very high in reference to data available from other sites across Africa. The author seemed to associate some fluctuation in MOI with rainfall patterns, so if entomological inoculation rate (EIR) data were available how did they match with MOI. Comparative studies of ITNs versus no ITNs in some areas did not detect any significant difference in MOI?

#### Presentation by Yazoumé Ye et al.

Yazoume Ye presented "on the risk of self-diagnosed malaria in urban informal settlements of Nairobi". The study aimed to assess whether malaria was a major health issue in Nairobi in order to fill the gap caused by a lack of recent data, and to find out whether there was a need for further malaria related research in the Nairobi slums. The risk of perceived malaria was studied in 7288 individuals in 2004 after a household survey. Participants were asked to report a maximum of 3 illnesses that occurred over the 15 days preceding the survey. An algorithm was established based on symptoms reported to diagnose possible malaria cases. Malaria was the leading cause accounting for 28% of sicknesses. The risk of self-reported malaria was higher in Viwandani and in the group 25-39 years old. There were also significant differences between ethnic groups, high self-reporting in some ethnic groups than others. The high reporting of malaria episodes in the age group 25-39 could be related to imported cases associated with migration. However, this data needed cautious interpretation. In conclusion, the author stressed that malaria was perceived as problem in communities living in informal settlements of Nairobi. Other malaria surveys needed to be conducted to provide more reliable data on the malaria situation in these settlements.

#### Discussion

Self-reporting of malaria was highest in adults aged 25-39 years. Given that this estimate was not based on clinical or laboratory diagnosis, there was a need to consider the role of HIV/AIDS in self-reporting of fever in the study communities.

#### Presentation by Mohamed Karama et al.

The results of a study on the distribution of bed nets in Rusinga and Gembe West in the Suba District were presented by Mohamed Karama from Kisumu. He outlined that the DSS site used as a platform for the study had been set up recently in the Nyanza Province, Kenya. The objective of the current study was to monitor the distribution of bed nets. The study area covered 50,000 inhabitants. Data on bed net ownership were collected during visit rounds for updating the DSS data. Preliminary analysis indicated that more than 55% of households in both Rusinga and Gembe did not have a bed net, suggesting that more efforts were needed to increase net coverage in this area, characterised by a high prevalence of malaria. Future studies would be planned to determine the proportion of individuals using ITNs, especially among children under five and pregnant women, to monitor the Abuja targets. Re-treatment of ITNs would also be examined.

#### Discussion

There were questions about who supplied the nets to the communities and whether the study examined net re-treatment rate. The presenter replied that most of bed nets were provided by non-governmental organisations and nets came already treated with insecticide. The net re-treatment rate had not been assessed, but there were plans to do so in the future.

# 5.2 Plenary Session 9 - Technical and methodological innovation from DSS sites

The following papers were presented:

- 1. Demonstrations of the robustness of DSS data. Peter Byass et al., Butajira
- 2. Use of Personal Digital Assistants (PDA) for collecting household-level data in the Western Kenya Health and demographic surveillance system (DSS), 2005-2006. **Barrack Aura et al., Kisumu** (CDC).
- **3.** Development of Personal Digital Assistant (PDA) application on demographic surveillance system (DSS) in Suba district, Western Kenya. **James K'Opiyo et al., Kisumu (NRS).**
- 4. Scanning of DSS forms and use of PDA for special module: Matlab experience. **HM**, **Golam Mustafa et al, Maltab.**
- 5. The feasibility of biometric fingerprint identification to survey and monitor demographic and health indices in highly mobile pastoral settings in Chad. **Daniel Weibel, Chad.**

#### Presentation by Peter Byass et al.

Question: How to you deal with systematic error?

**Answer**: They are also important for the DSS data and migration is one way of their occurrence. It is fair we must think about it.

**Question**: What happens if we have observations for only one year rather than 10 years? **Answer**: Yes, it is possible to simulate the error for one year's observation. However, to get a robust estimate it is better to have a large population sample.

Question: If you interview people on the road or at a farm, what about the use of GPS?

**Answer**: No problem. The fieldworker can record information when he arrives at the residence.

#### Presentation by Barrack Aura, et al.

Question: In a place with power, how do you recharge you PDA unit?

Answer: The PDA units are charged daily in the office and can last for three days without recharging.

Question: How do you deal with data security?

**Answer**: All the PDA units require a password to log in.

Question: Can verbal autopsy be done with PDA?

**Answer**: Yes, it is possible.

#### Presentation by Daniel Weibel

Question: What kind of computer do you need for fingerprint recognition?

**Answer**: You can use any type of current computer.

## 5.3 Plenary Session 10 - Mixed Bag

The following papers were scheduled for the session:

- 1. What is the role of DSS in identifying humanitarian crises? Edward Fottrell et al., Butajira.
  - 2. Burden of Disease in the Iganga/Mayuge DSS for 2005/06. Aloysius Mutebi et al., Iganga/Mayuge.
  - 3. Using a demographic surveillance system to enhance comprehensive adverse drug reaction case detection and associated treatment costs in rural Tanzania. Joseph Njau et al., Ifakara.
  - 4. Household out-of-pocket payments for illness: Evidence from Vietnam. Thuan Nguyen Thi Bich, Filabavi.
  - **5.** Do health care services in Africa correspond to the needs of populations? The case of the construction of a new hospital in a rural area of Senegal. **Malick Kante, Bandafassi.**

Only three out of the five papers scheduled for this session were presented. Below is a summary of the results and conclusions of the three papers.

#### Presentation by Edward Fottrell, and Peter Byass

The authors used data from the Butajira DSS in Ethiopia to investigate how the CDC crisis threshold definition of 1 death/10,000/day could be applied in DSS settings for the prospective detection of humanitarian crises.

The results showed:

- Unusual peaks in mortality in1998 and 1999;
- Mortality was related to unseasonal and low amounts of rainfall and consequent food insecurity;
- Mortality peaks reflected across all age groups but most marked in children under 5 (47.2% of the total);
- Mortality was mostly attributed to malaria or diarrhoea/malnutrition (determined using VA); The authors noted that:
  - There were periods when levels of mortality in the Butajira population met the CDC definition of a humanitarian crisis;
  - Butajira District did not convey the impression of a population in crisis;

• No humanitarian relief efforts triggered.

The authors concluded that:

- DSS data provided a rare opportunity for obtaining longitudinal individual population-based data before, during and after a crisis period;
- DSS uniquely positioned to play an important yet simple role in prospectively detecting crises.

#### Presentation by Aloysius Mutebi et al.

The authors of this paper used data from the Iganga/Mayuge DSS in Uganda and verbal autopsy (VA), social autopsy (SA), and years of life lost (YLL) tools to describe the burden of disease in the surveillance population.

The broad causes of death were as follows:

- 65% of the deaths were associated with communicable diseases, maternal, perinatal and nutrition;
- 27% were associated with non-communicable diseases;
- 5% were associated with injury;
- 3% were from undetermined causes.

## 5.4 Parallel Session - Mixed Bag

- 1. Adult self-reported health status versus performance-based health status (functionality) in the Kassena-Nankana District, Ghana and Pune District, India. **Pallavi S Lele et al., Multi** sites
- 2. The impact of bone and joint diseases on health-related quality of life of elderly persons: A population-based cross-sectional study in rural Bangladesh. **Masud Rana, Matlab.**
- 3. Opportunities and challenges of monitoring MDGs at DSS Sites Experiences from Ballgbarh, India. **Anand K, Ballagbarh**
- 4. Health Seeking Behaviour of People from Demographic Surveillance Sites in Asian Region. Sanjay Juvekar, et al., Asian sites
- 5. Social factors and overweight- Evidence from eight Asian INDEPTH sites. Abdul Razzaque, et al., Matlab.

## 5.5 Parallel Session 8 - Mixed Bag

This session had four papers, each with its own theme. They covered adolescence reproductive health, fertility, morbidity and burden of diseases.

- 1. Exploring the geographic dimension of adolescent reproductive health in the Kassena-Nankan District of Northern Ghana. **Solomon Atinbire, Navrongo.**
- 2. Fertility decline in rural South Africa: Another stalled transition? Tom, Moultrie, University of Cape Town.
- 3. Comparative estimates of disease incidence in rural Kenyan children: a case study of respiratory syncytial virus in the Kilifi DSS. J. Nokes et al., Kilifi.
- 4. The burden of disease: profile of residents of Nairobi's slums. Catherine Kyobutungi et al, Nairobi.

The first paper was presented by Solomon Atinbire, et al. from the Navrongo team. The paper was entitled: "Exploring the Geographic Dimension of Adolescent Reproductive Health in the Kassena-Nankana District of Northern Ghana". The paper used GIS to map out geographical differentials in reproductive health outcomes. The main findings were that disparities in access to information and services led to differences in knowledge of sexual and reproductive health issues. The discussion on this paper focused on whether the GIS and multivariate results could be presented separately as each of them had different policy relevance.

The second paper was by Tom Moultrie, et al. The papers examined the reasons for stalled fertility in South Africa. The paper used data from the Africa Centre Demographic Surveillance System in KwaZulu-Natal in South Africa to show how fertility had stopped declining even in rural populations although replacement-level fertility had not been reached. Possible reasons for the stalled fertility decline were suggested. The discussion on this paper focused on whether this was a new phenomenon in African demography where fertility would not decline as low as observed in Japan. Possible reasons for fertility not falling to replacement levels were suggested and these would need to be explored.

The third paper was presented by Catherine Kyobutungi from the APHRC group. The paper was entitled "The burden of disease profile of residents of Nairobi's slums". The authors used a tool developed by the Tanzania Essential Health Interventions Project to calculate the burden of disease and the interventions needed to address the burden. Among under- fives, pneumonia and diarrhoea contributed 38% of the burden. Among adults, HIV/AIDS, TB and injuries were the major causes of death. The presenter showed that the burden could be effectively reduced by using proven interventions.

## 6 Day 5, Friday, 07 September

## 6.1 Plenary Session 11

The following presentations were scheduled:

- 1. Funding opportunities at The Wellcome trust for developing-country scientists.
- 2. Progress of INDEPTH/Wits scientific development and leadership initiative.
- 3. Update on INDEPTH data system initiative.
- 4. Update on protocol development for integrating health facility and demographic surveillance data

## 1. Funding opportunities at the Wellcome Trust for developing-country scientists. Jacob Sweiry (Wellcome Trust)

The presenter informed the conference that the Wellcome Trust is a charitable organisation set up in 1936 to pursue biomedical research. The vision was to support research leading to discoveries that would impact on health. The philosophy was to start small and build up -for example Kilifi and South East Asia Wellcome Trust initiatives. The Wellcome Trust noted that the quality of scientific papers had improved and collaboration had increased over the last four years.

The University of Nairobi received the first Wellcome Trust funding in 1948. At present the Wellcome Trust was spending about f 450 billion per year to fund 3000 researchers in 50 countries globally. Funded researches were on infectious diseases, public health, social research, etc. Proposals had to demonstrate good science and should include a capacity building component.

Scientists could apply for research grants of 3 to 5 years. If the scientist was new, a UK partnership was necessary. There were strategic awards for 5 years (flexible) which could be provided to any applicant supported and recommended by the host organisation.

There were various fellowship schemes for MSc, PhD, postdoctorate and principal research. The fellowships partly covered salaries. Principal research required passing not only the science component from peer reviewers but also a rigorous oral interview with the Interview Committee. Masters fellowships were reviewed internally and awarded for thirty months. They required a good first degree, a sponsor and a supervisor.

Research training fellowships supported various cadres: intermediate fellowships, and mid-term career development were supported up to four years; for senior fellowships, up to five years renewable with half salary support.

Proposals to the Wellcome Trust must be of high quality, readable and understandable; a clear research question and why it was important; methods showing how the study would start and move forward. These proposals were put through a peer review process,, funding committee, other history and then short-listed for interview.

Proposals to facilitate public engagement to inform and influence policy to benefit society were also fundable. The other areas of interest to the Trust were ethics and biomedical research.

The Trust funded best research, best people, best science with a preference for those with collaboration and partnership. The Trust might also co-fund expensive projects. Participants were invited to peruse the Trust's website for further details, call the Trust or Jacob in person.

Questions: Can the University of Pakistan apply for a training grant for demography and bring people from outside?

Answer: The Trust would support developing demography within the university but would like to receive a multidisciplinary proposal, not just demography.

**Question:** Does the Trust support proposal development?

Answer: There is no mechanism to support such workshops. The few workshops the Trust had supported were not rewarding---- no fruits--- no outcome.

#### 2. Progress of INDEPTH/Wits scientific development and leadership initiative. KS Tint

The presenter informed the conference that an 18-month Masters programme at Witwatersrand University started in 2005 to provide the coming generation with knowledge in epidemiology, demography, biostatistics and leadership skills. It was a full-time course with five months' attachment at a selected DSS site. The DSS site provided mentorship (good science and leadership). The course had 20 modules.

The aim was to have ten students per year in order to operate economically. The first batch of five students had been sponsored by INDEPTH. There were five first year students and eight in the second year. DSS sites that had sent students into the programme were: Navrongo, Dodowa, Kisumu, APHRC, Vadu, Filabavi, Papua New Guinea. Four out five students had graduated. The other one was a late completion and would graduate in December. Old and new students met in June to form lasting contacts (ALUMNI).

So far the programme was doing well. It had established both South-South links as well as North-South links with such institutions as --- the University of Washington, USA, University of Colorado, USA London school of Public Health, WHO, etc. However, the programme had not succeeded in recruiting the economical class of ten students per year and more field support was required.

The majority of the DSS (25 out of 34) saw the need for the training but did not have suitable candidates for the programme, and their senior staff did not have the time to supervise the students during attachment.

Although the deadline for 2008 had passed, it had been extended to the end of September, 2007 to give sites a chance to send in students.

Question: Is it possible to reduce the length of the course from eighteen to fifteen months?

**Answer:** We shall think about it.

Question: Would you like to have an external reviewer for the benefit of future funding? Answer: External review will be done next year, 2008.

Question: Would you like to consider candidates from outside the DSS?

Question: Is it possible to send students from Asian universities to specialise in certain specific areas?

**Answer:** This possibility will be considered.

**Question**: Is possible to have a bridging module? For example, Language: English, French and Portuguese, or a good diploma candidate?.

Answer: Point well taken.

Other DSS sites were encouraged to take up the programme. When evaluating the impact of the programme, it was important to consider responsibilities, promotions etc.

**Question:** Is it possible to have a short term certificate module?

Answer: Not on board yet, but yes, it's possible.

## 3. Update on INDEPTH data system initiative - Update on protocol development and integration

The proposal was being developed for one year. It started in June 2006 and a workshop in August 2006 in Accra paved the way for a concept paper. In February 2007, the Wellcome Trust funded a workshop in South Africa. Its aim was to improve data capture, management, processing, and analysis.

The proposal was in the last stages of editing and submission. The group was lead by Corbus.

This was going to be a participatory process and would require field testing.

Look into implementing paper to PDA data collecting methods.

When the full proposal was ready, the final version would be funded by the Wellcome Trust with collaborators.

#### **Discussions**

**Question**: Where is recognition for efforts put in by DSS sites?

**Answer**: We shall look into it.

Platform to allow sites to share data---- easy to retrieve--- sites will have control of data.

**Question**: How do we share data?

**Answer**: We have moved from HRS to SQL. Hoping DSS sites will support and participate in it to make it work.

#### 4. Health facility information and demographic surveillance data. Henry.

A project to link DSS data and health information at health facilities was in the making in Tanzania. Possible ways of linking and identifying individuals included use of fingerprints, optical, photographs. Clinical data would be captured either with paper or electronically by PDA or laptop.

Staff would be required to capture data, update visiting information, extract data from health facility to DSS system, etc. For smooth integration it would be necessary to have a uniform format for data collection.

Staff requirements included a receptionist, a medical officer, a data entry clerk and an IT technician.

Many challenges were anticipated: acceptability, human resource capacity, access to hospital data, sustainability, etc.

Next steps: to learn from other sites, take an inventory of existing systems. Decide on software to implement the programme.

**Question:** How will the system work in health facilities without electricity?

**Answer**: The project will start with district hospitals where 99% are expected to have electricity.

**Question:** How will you identify infants using photos given that they will change with time? **Answer:** We shall use mothers' names to identify the child using gender and date of birth.

**Question:** Is it possible to fingerprint people in the entire DSS?

Answer: We shall deal with these issues as they arise.

**Question:** How will you tackle the problem of different indicators at the health facility and at the DSS?

**Answer**: We shall consult with the health facilities and agree on common parameters.

**Comment:** Share the idea with health system. Analyse what they do and show what the new system will do. Seeing the benefit of the system will increase acceptability. There are plan to woo the health system by providing the electrical medical system free of charge.

## 6.2 Plenary Session 12 - Working Groups feedback and closing

#### 6.2.1 Migration and Urbanisation Working Group

The presentation was given on behalf of the group by the leader, Mark Collinson of Agincourt DSS. He noted that the Migration and Urbanisation Working Group aimed to promote migration research at INDEPTH sites and that the immediate objective of the group was to produce a monograph on migration and urbanisation using DSS data. He noted that the monograph would look at various issues, including key substantive areas such as migration and health, migration and poverty, migration and social change, etc.

He also noted specific challenges that they had faced in their attempt to produce the monograph, in particular, the problem of comparability of migration data. He mentioned that because of differences in definitions, they had faced the challenge of making comparative analyses across sites. He also mentioned the inadequacy of technical capacity in some of the sites which had delayed the work .

Nevertheless, the presenter mentioned that much progress had been made and the chapters were being reviewed though there was still some work outstanding before the monograph would be ready for publication.

#### 6.2.2 Mental Health Working Group

Don de Savigny presented a recorded note on behalf of the convener of the Mental Health Working Group and reported at the feedback session. He noted that the reason for the formation of the Mental Health Working Group stemmed from the fact that the burden of mental health problems was quite high but had not been given the attention it deserved. He, however, noted that a series of articles on mental health would be coming out in *the Lancet* which, it was hoped, would draw attention to the issue.. The articles would be distributed when they appeared. He also mentioned that a bibliography of over 1,600 publications was being compiled and that a bibliometric analysis of this database would be done to determine the prevalence of mental illness. The group also planned to see if they could contribute information on mental health to the resource kit when it was being revised.

Finally, he mentioned that Kilifi had developed a proposal on epilepsy involving five INDEPTH sites and that Charles Newton was the Principal Investigator.

#### 6.2.3 DSS-Universities Collaboration Working Group - Francis Dodoo

The DSS-Universities Group was led by Francis Dodoo. He noted that the collaboration went back to 2006 when representatives from select universities in Ghana, Kenya and South Africa met with colleagues from DSS sites from those countries to brainstorm on how to draw on their respective strengths to build capacity for the analysis of DSS data. He mentioned that a number of constraints had slowed down progress despite the fact that INDEPTH received funds to support the collaboration. Some of the constraints identified included:

- Limiting proposals to \$25,000;
- Initial call phrase as if universities were supposed to help sites;
- Impossibility of forcing teams to collaborate. There had to be a willingness to collaborate. This meant that the DSS-Universities Group needed to start talking more and agree on the mutual benefits of collaboration.

He mentioned that the two groups had indeed started talking and he was hopeful that this dialogue would result in some concrete projects.

#### 6.2.4 Reproductive Health Group - Eliya Zulu

Eliya Zulu of APHRC reported on behalf of this group. He reported that this group initiated work in three areas but had not made much progress since its inception. The three areas he mentioned were:

- Reproductive health;
- Maternal health;
- Fertility research.

He noted that APHRC received funding from The British Council and brought six INDEPTH sites to a workshop in Nairobi to discuss areas of fertility research and analysis. The interest was to look at fertility issues, particularly in relation to birth intervals and their impact on maternal health, adolescent reproductive health, etc. He mentioned that their assumption prior to the workshop was that sites would collect reproductive health data but this, he noted, was a flawed assumption.

Nonetheless, he said, there was strong interest from members and they would strengthen efforts to get the team to move the group forward. He added that they would form a committee to define the issues and take this to a proposal for the next level. Leadership issues were also discussed. He ended by urging site leaders to endeavour to get information to young scientists.

#### 6.2.5 Social Autopsy Working Group

This is an interest group working to galvanise support for trying out a tool that has been tested at the Iganga/Mayuge site in Uganda by Karin and colleagues. Karin, who presented, mentioned that unlike verbal autopsy, the social autopsy tool used unstructured probing questions to establish all the social processes that took place and the care-seeking that went on prior to death.

The tool had already been tried in a number of places including places in Uganda. She reported that the next step was to take an inventory of existing tools, review them, come up with a standard format and develop an analysis plan.

#### 6.2.6 Asia NCD Working Group

Siddhi Hirve of Vadu presented on behalf of the group. He mentioned that the group, which was formed in 2005, had so far been quite successful in using WHO STEPS approached to collecting data. Analysis of the data had been carried out and a paper had been published from that effort. He added that they were now trying to link up with resource persons and see how they could take the work even further. According to him, two proposals had already been submitted – one to The Wellcome Trust and the second to AusAID. Their aim was to go into intervention or behavioural research and there was need to link this work with the Adult Health Group.

#### 6.2.7 Adult Health Working Group

Steve Tollman gave an update on the work of the Adult Health Working Group. He reported that the group met three times during the AGM and that data collection was nearing completion from all sites. An analysis plan was being drawn up and data analysis would begin quite soon. What remained to be done, according to Steve, was the preparation of the datasets. A workshop was being planned for April, 2008. He also reported that harmonising longitudinal work with work in the developed world was needed, and that a broad portfolio of funders was being sought to achieve this.

### 6.2.8 Mortality Monograph Working Group

Momodou Jasseh made a passionate appeal to site leaders to try and contribute the data needed for the revision of the mortality monograph.

#### 6.2.9 Vaccines Working Group

The Vaccines Working Group is led by Peter Aaby. According to him, few sites were collecting data on vaccines. He mentioned that he had analyzed data from a number of sites and had visited others to determine what data were being collected. He noted that as a result of analysis of immunization data which had generated a good deal of controversy, an analysis of vaccines and methodology workshop would be organised by Peter Smith at the LSHTM Recommendations from this workshop might feed into a tool kit and, it was hoped, lead to multi-site observational studies in the future.

#### 6.2.10 SAC Chair's remarks

The Chair of the SAC, Dr.Wendy Ewart, of Imperial College, London, thanked the hosts for a wonderful meeting and the SAC for their participation in the week's activities. She mentioned that the SAC had met members of the Board during the week to seek their opinion on how it could be more helpful to them. She said the meeting had been very collegial. She also noted the richness of the scientific output and productivity during the week. She recognised the expertise of the SAC and urged members to put their expertise to the service of INDEPTH.

#### **6.2.11 Poster winners**

The best young scientists' poster award was jointly won Mr. Daniel Tindabel and Dr Abdhala Ziraba from Nairobi DSS.

APHRC best poster award went to Rashid A Khatib of Ifakara DSS for his poster on "Effectiveness of existing net distribution strategies for achieving community wide coverage and protection in rural Tanzania".

#### 6.2.12 Comments from funding partners

At this point the funding partners present were asked to make a few remarks about the AGM. Jacob Sweiry of the **Wellcome Trust** noted that the data linkage proposal had huge potential and that it offered great opportunities for lots of work to be done. He noted that the issue of data access and sharing that had been talked about was not about giving up the data but about sharing information with others to analyze with as few restrictions as possible. He also mentioned that the DSS-Universities concept was very important, and needed to be taken forward. He suggested that it might be useful to organise scientific writing workshops during future AGMs so young scientists could take advantage of the experienced researchers and scientists who usually attended the meeting.

Jessica Milman of **The Bill and Melinda Gates Foundation** expressed her foundation's willingness to make commitments to INDEPTH and that INDEPTH offered great opportunities and needed to harness the full potential of this unique platform. She noted that she was proud to be part of the work. She conceded that there would be challenges but that various partners were willing to be part of the process of providing assistance.

#### 6.2.13 Board Chair's remarks

The new Board Chair, Dr. Seth Owusu-Agyei promised to continue to support INDEPTH and said that there was a need for all concerned to cooperate towards taking the Network to the next level. He mentioned the need to transform the Network's governance structure to make it more relevant and marketable. He noted that there was still an empty seat on the Board and undertook to ensure that it was filled.

On the SAC, he said their role was critical in helping to define and shape the scientific agenda of the Network and urged the committee to support it in the best way possible. He mentioned that the Network needed core funding at the Secretariat and that the Board would endeavour to achieve this. He also noted that the Network needed to improve on its activities, especially its publication record. He also appealed to site leaders to try and make available to the Secretariat their annual reports. He called on working group leaders to accelerate their efforts to write proposals to fund their activities. Finally, he mentioned a number of new areas that needed to be researched into, including neonatal mortality, data systems and education. He concluded by announcing that Ifakara DSS had offered to host the next AGM in Tanzania and that the outgoing Board Chair had agreed to co-fund it with a US\$75,000 contribution.

#### 6.2.14 New Executive Director

Dr. Osman Sankoh thanked outgoing Executive Director for setting him such high standards and promised to live up to the challenge. He stressed the need to contribute to cross-site activities and

that sites should support the Secretariat so it could be of greater help to them. He stressed the importance of collaborative efforts.

He gave a brief profile of the strategic plan and noted that there were new initiatives about to be launched which would require more work. He laid emphasis on his vision which was to strengthen individual and institutional capacities. He however, noted some challenges that needed to be overcome, such as:

- 1. How to make working groups more effective;
- 2. The need to identify new cross-site research activities;
- 3. The Africa attraction: what can be done about Asia?
- 4. Data sharing issues;
- 5. Core funding for the Network;
- 6. The need to interface with regional organisations;
- 7. Making sites appreciate the value-added;
- 8. How to make sites identify themselves with the Network,
- 9. Lean size of the Secretariat and programme expansion.

Finally, he thanked the organisers for a well organised AGM. He also thanked the staff of the INDEPTH Secretariat for their hard work over the years and promised to maintain a collegial working relationship with them.

#### 6.2.15 Remarks from Alex Ezeh on behalf of the host institutions

He thanked all the sites in Kenya – Nairobi, Kilifi and Kisumu – which had worked so hard in a collaborative fashion to make the AGM successful. He thanked in particular, Dr. Yazoume Ye and Dr. Jean-Christophe Fotso, the overall coordinators from APHRC, Mr. Joseph Gichuru, Finance Manager, who headed the Finance Subcommittee, Ms. Lillian Okoth, Human Resources Officer, APHRC, who headed the Hospitality Committee, Ms. Nkatha Karichu, Administrative Assistant, APHRC, who headed the Transport Committee, Mrs. Rose Oronje Communication Officer, APHRC, who was in charge of Communication, and finally, Ms. Gladys Aruwa-Nyabundi, the conference co-coordinator, for a job well done.

The conference ended on Friday, 07 September, 2007 at 15h00 with a delightful feeling that a successful event had taken place.