

**REVIEW OF INDEPTH NETWORK'S MISSION ON POLICY
ENGAGEMENT AND PRACTICE**

Submitted to the William and Flora Hewlett Foundation

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List of frequently used abbreviations

AU	African Union
CBO	Community Based Organisations
CERS	Communications and External Relations Strategy
CDC	Center for Disease Control
CHPS	Community-based Health Planning and Services
CRVS	Civil Registration and Vital Statistics
CVD	Cardio Vascular Diseases
DALY	Disability Adjusted Life Year
DHS	Demographic and Health Surveys
GHS	Ghana Health Service
HAALSI	Health and Ageing in Africa: Longitudinal Studies of INDEPTH communities
HBC	Home based care
HDSS	Health and Demographic Surveillance System
HIB	Haemophilus Influenzae type B
IDRC	International Development Research Centre
INESS	INDEPTH Effectiveness and Safety Studies of Antimalarials
IPUMS	Integrated Public Use Microdata Series
IRD	Institut de Recherche pour le Developpement
ISC	INDEPTH Scientific Conference
ITN	Integrated Treated bed-Nets
IUSSP	International Union for the Scientific Study of Populations
LMIC	Low and middle income countries
MOH	Ministry of Health
MRC	Medical Research Council
NCD	Non communicable diseases
NEPAD	New Partnership for Africa's Development
NGO	Non-governmental organisation
NIH	National Institutes for Health
PCV	Pneumococcal conjugate vaccine
SAC	Scientific Advisory Committee
SSA	Sub-Saharan Africa
TDR	Special Programme for Research and Training on Tropical Diseases
VA	Verbal Autopsy
WDF	World Diabetes Foundation
WG	Working Groups
WHO	World Health Organization

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EXECUTIVE SUMMARY

The INDEPTH Network, with its 49 Health and Demographic Surveillance Systems (HDSS), is unique in its scale and capacity to produce longitudinal data about millions of people in low and middle income countries (LMIC). The potential for HDSS to inform policy decisions and programs is significant, and some HDSS have been successful at generating evidence that ultimately guides policy-making. However, little is known about what conditions must be met by HDSS to achieve success in this regard. The William and Flora Hewlett Foundation commissioned a review to help the INDEPTH Network to determine how the 36 HDSS in sub-Saharan Africa (SSA) translate their findings to maximize impact on policy and practice, and how the Secretariat supports member centers that run HDSS to achieve this goal. The review focused primarily on the translation of research into policy and practice and did not attempt to assess the overall performance of the INDEPTH Network and its Secretariat.

The review defined policy and practitioner impact as occurring at three different levels:

- At the *local level* where the HDSS centers directly interact with local policy makers and practitioners;
- At the *national level* through the combined outreach of individual or groups of HDSS centers located in one country possibly with the assistance of the Secretariat; and
- At the *international level* where impact can be through findings in peer-reviewed journals, provision of internationally comparable data sets, and direct engagement of INDEPTH scientists or Secretariat staff with international organisations and major funding organisations.

The methodology of the review included discussions with the INDEPTH Board of Trustees and Secretariat staff, interviews with staff from seven selected HDSS centers, assessment of six impact case studies provided by the Secretariat and selected HDSS centers, interviews with end-users of research findings, and document reviews.

Key Findings

Translating research into policy and practice is a strategic objective of the INDEPTH Network but progress towards this objective has been weak despite several efforts into this direction in recent years. Over the last ten years, the Secretariat has placed its highest priority on quality control of the data and standardization of data collection methods. Direct policy outreach to national and international decision makers has taken a secondary role. This was a wise choice because the credibility of the data and the resulting analysis are important prerequisites for any kind of policy impact. In 2013, the Network launched the INDEPTH Data Repository and INDEPTHStats, opening up online access to core demographic indicators and some data. This is a good start and, as more harmonized data are placed in the Repository, the scientific community will start to make use of the data on a larger scale.

In its Strategic Plan for the period 2013-16, the Network has committed to “tailoring, packaging and directing research outputs, as appropriate, for different audiences and stakeholders so as to bridge the

gap between research findings and policy-making”¹. The implementation of this objective is yet to be defined but the Network has re-launched its *Research to Policy Working Group*. With strong and effective leadership, the rejuvenated working group could play a role in supporting the Network to fulfil this objective.

While our review found that the majority of the HDSS are producing high quality peer-reviewed research, translation of the research findings into policy and practice varied. At a deeper level, a key challenge for the INDEPTH Network is to identify and address research and policy questions for which the unique longitudinal and multi-dimensional platform of the HDSS (which is expensive to run) is utilized as an indispensable component. Several of the cases that we assessed (for example interventions to reduce prevalence of certain diseases) could have also been gained from much simpler research designs. This is in part a reflection of the funding bias, which is at the moment predominantly for specific health-related projects. The majority of these projects do not utilize the full potential of the HDSS setting including its extensive demographic components.

This review has identified a number of factors that appear to be linked to how successful HDSS are in translating research into policy. These include:

- i) Whether a center is autonomous, locally owned, or owned by institutions in the global north, which in turn determines the primary audience for the research;
- ii) The source of funding, with that from research end-users most likely to lead to use of findings for policy and practice;
- iii) The researcher-policymaker relationship; and
- iv) The presence of staff with skills in policy engagement and communication at the HDSS center.

The role of the Secretariat in translating research into policy and practice has so far focused on supporting member centers with training events for staff involved in data collection, data management, and analysis. While the Secretariat has convened workshops on communication skills for researchers, there was a general view from staff and researchers that more could be done to enhance the profile of the Network and HDSS centers among policy makers and funders.

Recommendations

1) In addition to being responsive to specific donor- driven and mostly exclusively health-related projects, the INDEPTH Network and its funders should invest in the conceptualization of directly policy relevant research questions that optimally utilize the great capabilities of the longitudinal and multi-dimensional HDSS platform. One example for such an effort could be the highly policy relevant study of the interactions between health, education and fertility at the micro and community level. While the scientific literature suggests that these three factors are greatly interconnected (with effects going in all

¹ INDEPTH Network. Delivering Better Health Information, Driving Better Health Policy. The Past, The Present, The Future. Accra, March 2014, page 11.

directions) the empirical assessment of these has been hindered by the need for a complex longitudinal and multi-context study design of precisely the sort that HDSS offers. Another example is untangling the causal relationship between reproductive health and women's economic empowerment. New insights on the nature of these inter-relationships would be of highest policy relevance, from the global level Sustainable Development Goals down to the design of community-level health and social services.

2) A challenge that the Secretariat faces in coordinating and leading network-level work on translating research into policy and practice is the lack of staff at the Secretariat with appropriate skills in policy engagement. While funding is one part of the problem, the Secretariat has been trying unsuccessfully to recruit a senior policy and communications analyst.

Our recommendation is that the Secretariat should intensify efforts to recruit a policy dialogue and communication specialist with knowledge of the international policy arena. While it is desirable that the staff member is based at the Secretariat, another option might be to recruit one or two experienced people from HDSS centers on a part-time basis.

3) The Network does not have a clearly defined strategy for policy engagement, and as a result, most of the activities in this area are ad hoc making it difficult to track impacts. Specifically, the Network has not yet identified the primary stakeholders it wishes to influence nor how to proactively communicate and engage with them. In 2009, the Network developed a Communications and External Relations Strategy which is a useful component of a Policy Engagement Strategy, but it is not clear if this strategy is being implemented or monitored. There has been limited interaction with global high-profile bodies (e.g. World Economic Forum) and while contact has been established with major regional bodies in Africa and Asia (e.g. NEPAD/African Union, Asian Development Bank, African Development Bank), there is potential for INDEPTH to do more to influence these stakeholders.

We recommend that the Network should develop a policy engagement strategy which clearly identifies the potential stakeholders and beneficiaries of INDEPTH's products, what activities are necessary to ensure that there is impact, and an evaluation plan. In identifying its stakeholders, the Network may want consider mapping stakeholders (e.g. funders, policy actors, media, civil society, academic community and so on) and it should develop action plans to engage with each group. On policy actors, INDEPTH should look beyond WHO and ministries of health.

We further recommend that the Network should review its Communications and External Relations Strategy to align it with the Network's revised strategic objectives. There should be clarity between the actions that are being led by the Secretariat and those led by center members. Annual action plans would be a useful way of managing and the implementation of the strategy.

At the national level, we see the role of the Secretariat as being strategic but in the background, supporting the HDSS centers. At the international level, the Secretariat should play a lead role in targeted and direct engagement with the international policy and donor community.

4) A distinction between HDSS centers that are more successful in policy engagement and those less engaged is that the former use a proactive approach to policy engagement, with strong links with the

stakeholder beneficiaries. HDSS that develop trusted relationships with end-users of research are more likely to be successful in translating research into policy and practice. Where researchers are trusted, the relationship can be bi-directional, with stakeholders sometimes making the first move.

We recommend that HDSS centers that have not yet developed policy engagement strategies should be encouraged to do so, being clear of the audience they wish to influence and developing trusted relationships with stakeholders.

5) With regards to publications from HDSS centers, the “INDEPTH” brand is not highly visible. Although the INDEPTH Data Repository has citation information for more than 3,000 journal publications published by researchers affiliated to HDSS centers, the majority of these do not mention their affiliation to INDEPTH. In contrast, researchers often acknowledge their connection to the Network when applying for grants as there is a perception that this enhances the chances of success.

Since research findings from HDSS centers published in peer-reviewed journals are a key outlet that has the potential to influence the international state of the art, we recommend that efforts should be made to increase the visibility of INDEPTH in the publication and dissemination of such findings. It may be a promising idea to occasionally publish (in the form of reprints or summaries of findings) a bundle of such scientifically influential studies and distribute them under the INDEPTH logo.

We also recommend that the Secretariat should identify “cross-cutting products” that it can spearhead in dissemination for policy translation. Repeatedly, the “cause of death” work was mentioned as one such example that the Secretariat should focus on.

6) Recently, the Network has launched the INDEPTH DATA Repository and INDEPTHStats which have the potential to increase utilization of the data by the wider research community.

We recommend that efforts should continue to make more surveys and more standardized variables available so that over time this could become one of the standard references for international comparative studies. Investments in software to reduce the time between data collection and analysis could reap huge rewards. We recognize that dealing with longitudinal data is more challenging than for example, the widely used IPUMS and DHS databases, but ultimately it must be the goal to make as much INDEPTH data as possible available to the international research community in order for it to become a significant resource for international policymaking.

7) Funding for research usually ends with data collection or publication of findings in journals without any funding for impact activities. Also, because of the lag time between the end of a project and realization of impact, there is often no money left for policy engagement activities.

Our recommendation to the Network is to ensure that project costings include budget lines for policy engagement and impact-related activities. Periodically, the Secretariat could apply for follow-on funding to “mine” INDEPTH’s research for policy engagement and societal impact. Examples of such opportunities include the Wellcome Trust International Public Engagement grants and grants for systematic reviews.

1. INTRODUCTION

INDEPTH is a global network of 49 Health and Demographic Surveillance Sites (HDSS) run by 42 centers in 20 countries in Africa, Asia, and the Pacific. Twenty-eight of the centers operate 38 sites in sub-Saharan Africa. In 2013, the William and Flora Hewlett Foundation commissioned a review to determine how the Network's HDSS in sub-Saharan Africa translate their findings to maximize impact on policy and practice, and how the Secretariat supports member centers that run HDSS to achieve this goal.

Purpose of the Review

The purpose of the review was to determine the conditions that must be met for HDSS in SSA to have policy relevance and how the INDEPTH Secretariat supports member centers that run HDSS to achieve this goal. Specific objectives were to:

- Assess the extent to which HDSS run by INDEPTH member centers function as robust research platforms and how successful they are in translating research into policy and practice.
- Describe the characteristics of HDSS that are successful in translating findings into policy and practice (at local, national, and international levels), and what factors contribute to their success.
- Identify how the Secretariat supports HDSS that are engaged in policy engagement and how participation in INDEPTH adds value to HDSS's work in this area.
- Explore the factors that influence (positively and negatively) the Secretariat's ability to support HDSS, and which barriers to success the Secretariat can realistically address for HDSS that are less engaged in policy engagement.
- Describe the role of the Secretariat in engaging with external (policy, academic, funding bodies) stakeholders and how successful the Secretariat has been in these engagements.

The full terms of reference are in Appendix 1. The report is structured as follows: Section 1 provides the introduction, purpose of the review, and the context. Section 2 describes the methodology of the review. Section 3 focuses on the role of the Secretariat in translating research into policy while Section 4 describes examples of impact case studies from selected HDSS centers. Section 5 describes the barriers to translating research into policy, and Section 6 discusses the challenges and recommendations.

About the INDEPTH Network

The International Network for the Demographic Evaluation of Populations and Their Health (INDEPTH) was established in 1998 and since its inception, its member sites have gathered demographic and health information from more than 3 million people from LMIC. It is the only network of its type in the world, and represents remarkable investment in infrastructure that is capable of generating rich longitudinal data on health and population over time. Individually, the HDSS collect data in relatively small geographic locations, some of which date back as early as the 1970s. A major strength of INDEPTH is its capacity to produce longitudinal data about millions of people in a range of settings in low and middle

income countries. The governance of the Network includes an Executive Director (ED) and a Secretariat based in Ghana, a Board of 11 Trustees, and currently 17 members of the Scientific Advisory Committee. Each of the HDSS center members has a leader who participates in the annual general meeting.

INDEPTH's vision is "to be an international network of demographic research institutions that provides health and demographic data to enable developing countries set health priorities and policies based on the best available evidence ..."². The Network's strategic objectives are:

- i) To strengthen the capacity of INDEPTH member centers to conduct longitudinal health and demographic studies.
- ii) To stimulate, co-ordinate and conduct cutting-edge multicentre health and demographic research.
- iii) To facilitate the translation of INDEPTH findings to maximize impact on policy and practice.

The potential for HDSS to inform policy decisions and programs is immense. In countries with weak civil registration and vital statistics (CRVS), they can provide data useful for tracking population events and social changes. HDSS, through their longitudinal surveillance of populations, are an important platform for intervention studies and for evaluating impacts of policies and programs. They also have the potential to advance understanding of the inter-linkages between demographic, health, and social variables.

Translating Research into Policy and Practice: Considerations

In this review, we assume that three key processes are necessary to translating research evidence to inform policies and practice. These are: production of high-quality research which has policy relevance; appropriate communication of the findings in formats that are relevant to the users; and effective researcher- end-user engagement. Markers of high-quality research are *validity*, usually endorsed by peers through the peer-review process in scientific journal publication, and *replicability*, which is possible when other scientists have access to the data to replicate analyses or experiments. Indicators of sustained high quality research generation include the number of publications in scientific journals, citations, adoption of methodology by other researchers, inclusion of papers in robust systematic and critical reviews (e.g. Cochrane systematic reviews, citation in official documents, and significant prizes.

Appropriate channels of communication to end-users of research and intermediaries may include: stakeholder dissemination workshops, succinct policy briefs, face-to-face briefings, media interviews, press releases, giving expert evidence to committees, website summaries, social media and so on. The third process of researcher-end user engagement can take many forms, including arms-length engagement to co-production of research findings. In good researcher-end-user relationships, end-users may proactively demand research evidence or commission research projects, and researchers become the "go to" place for high quality advice and information. Mature relationships will often involve

² INDEPTH Network. Annual Report, 2012. Accra Ghana, page 7.

researchers being invited to participate in most steps of the Policy Cycle (formulation, decision-making, implementation, monitoring and evaluation, and agenda-setting).

Indicators for assessing the strength and quality of the researcher-end-user relationships may include: researchers being invited to membership on policy-making or agenda-setting committees, membership on program boards, advising or drafting policy documents, appointment of policy stakeholders on advisory boards to inform research, or co-authorship with end-users. The three processes are not linear as Figure 1 (with inter-dependent components) illustrates; high-quality research evidence can lead to good researcher-user engagement and vice-versa.



Figure 1: Inter-dependent Processes in Translating Research into Policy and Practice

There are potentially many types of impact that INDEPTH research can generate. Examples include impact on policies, legislation, quality of life, cost, public understanding, behaviour change, and so on. Equally, there are many domains (health, education, economic, environment) on which the work of HDSS might have influence (see Table 1 below).

With regards to the level of influence, we distinguish between three levels of influence: the *local community* where evidence from HDSS could be directly relevant to local practices, policies and administration (e.g. changing health behaviour in the community, improving practice in local health facilities and in local schools); the *national arena* where findings might lead to amendments of existing programs or creation of new ones; and the *international policy and donor community*, where results that can be generalized across sites and countries may be most relevant.

Table 1. Examples of Types of Impact on Policies and Practice Applicable to HDSS Centers³

Domain of Impact	Description
Health, Demography, and Wellbeing	<ul style="list-style-type: none"> • Improved registration of vital events • Reduced unmet need for contraception • Reduction in fertility • Influence on child survival • Improved quality of life • Changed behavior towards harmful practices (e.g. female genital mutilation, early marriage) • New drugs, lifestyle interventions developed • Improved provision or access to welfare services • Influence on public health policies • Improved client- health provider interaction • Development of new methods/indicators for measuring health and wellbeing (e.g. cause of death)
Economic	<ul style="list-style-type: none"> • Policies to improve schooling outcomes or reduce child poverty • Influence on childcare policies • Policies to improve female labor participation • Reduction in costs of treatment and healthcare
Organizational	<ul style="list-style-type: none"> • Influence on professional standards, guidelines, or training • Improved effectiveness of workplace practices • Changes to management and/or resource allocation leading to improved service delivery
Culture and Society	<ul style="list-style-type: none"> • Shaping political or public debate • Public attitudes and values shaped • Influence on social policies leading to improved social welfare
Environment	<ul style="list-style-type: none"> • Environmental policies influenced • Improved management of environmental risks or hazards
Public Policy and Law	<ul style="list-style-type: none"> • Legislative change • Confirmation, implementation, or withdrawal of public policies • Shaping or influencing public policy • Influencing policies and working of non-governmental organizations (NGOs)
<p>Generic examples of evidence to corroborate impact</p> <ul style="list-style-type: none"> • Communication from policy makers and practitioners • Citations in policy documents, public discussion, official documents, media • Citation by international bodies such as WHO, and UN agencies • Public debate in the media; debate among practitioners • Documented change to professional standards • Quantitative data on changes in outcomes (e.g. improved survival rates, increased contraceptive prevalence rates) • Data on cost-effectiveness and organizational performance, client satisfaction data • Sales of new products 	

³ Adapted from Research Excellence Framework documents, Higher Education Funding Council, 2012, UK.

2. METHODOLOGY OF THE REVIEW

Below we describe six steps which we used to conduct the review.

a) A short survey to identify HDSS centers in sub-Saharan Africa who were engaged in translating research into policy and practice. From the survey responses, we sought to identify two groups of centers: those who were very engaged in translating findings into policy and practice (Group 1) and those who were less engaged or where information about their policy engagement work was not highly visible (Group 2). There was a 48% response rate from the survey, and among the non-respondents there were centers that we knew to have had impact on policies and practice in their countries. Therefore, our final selection also took on board our knowledge of the policy engagement work of the individual centers, and the Secretariat's assessment (see Table 2 in Appendix 2 for a brief profile of the African HDSS centers). Four centers were chosen to represent Group 1: Agincourt HDSS (operated by MRC/Wits Rural Public Health and Health Transitions Research Unit in South Africa), Nairobi Health and Demographic Surveillance System (operated by the African Population and Health Research Center, Kenya), Dodowa Health Research Center (Ghana), and Manhiça HDSS (Centro de Investigação em Saúde de Manhiça, Moçambique). In Group 2, we selected Farafenni HDSS (the Gambia), Iganga/Mayuge (Uganda), Nouna (Burkina Faso), and Kiltie Awlaelo (Ethiopia).

b) Case studies were developed by the centers in Group 1, to provide examples of specific impact on policies and practice within the past five years. These case studies described the underpinning research, the nature of the impact, sources to corroborate the impact, support from the Secretariat, and sources of funding. The Secretariat also prepared two impact case studies to demonstrate its role in enabling the Network to translate research into policy and practice.

c) Documentary review and tracking of policy documents, technical reports, and websites to track the evidence to show that research from HDSS and/or the INDEPTH Network has had an impact on key organizations such as World Health Organization, UNICEF, UNDP, the World Bank and so on.

d) Discussion with INDEPTH Secretariat and Board of Trustees to document how they operationalize the strategic objective of facilitating the translation of evidence to maximise impact on policy and practice.

e) Interviews with HDSS representatives: For Group 1 the interviews or email discussions were used for further information on the process of generating impact, what the catalysts were, and the role of the Secretariat and other networks in enabling impact. Interviews with Group 2 representatives sought, firstly, to establish the level of policy and practice engagement and, secondly, to identify barriers to translating research into policy and practice.

f) Interviews with end-users of HDSS-generated evidence. These interviews were used mostly to corroborate reports of the impacts in the case studies. For each impact case study, two end-user stakeholders were identified and approached. The interviews also sought to understand how users perceive the relevance of the HDSS' research for policy formulation or programming in general, and

whether or not the channels through which they received research findings from HDSS and INDEPTH were in appropriate formats. A full list of people who were interviewed or gave evidence can be found in Appendix 4. Diagrammatically, the process of the review is summarised in Figure 2.

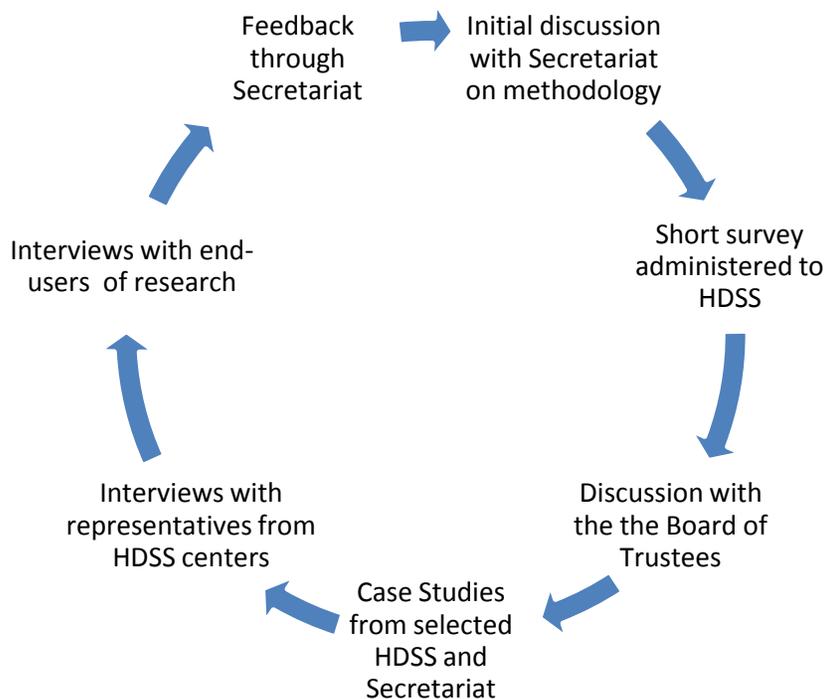


Figure 2: The Process of the Review of the INDEPTH Network’s Policy Engagement

3. THE ROLE OF THE SECRETARIAT – Translating Findings into Policy and Practice

In this section, we focus on the role of the Secretariat in translating research into policy and practice and how it supports the work of individual HDSS centers. We report mainly on the discussions with the INDEPTH Board of Trustees (26-27th March 2014, Stockholm), discussions with staff at the Secretariat (Accra, 9th -12th April 2014), two impact case studies prepared by the Secretariat, and information gathered from discussion with staff at selected HDSS centers.

How does the INDEPTH Network operationalize its policy engagement objective?

Translation of research into policy and practice has always been a core objective of the Network. In 2003, a Research to Policy INDEPTH Working Group was formed to help the Secretariat to coordinate and spearhead policy engagement activities. However, it became clear very quickly that one component of the ‘*translating research into policy*’ process, that is the generation of high quality research findings,

could not be endorsed for all HDSS with confidence. The quality of data was very variable. At the same time, the international research community was getting anxious at what it perceived as a reluctance of the Network to share data⁴. This prompted the Network to prioritize collection of high-quality data which it did through training on data collection and management, development of harmonised tools for the demographic surveillance, and master's level training for INDEPTH scientists. It was not until 2010, with the financial support of its major funders, that INDEPTH felt confident enough to start producing network-level aggregate statistics and to start sharing some aggregate-level data. As one of the Board of Trustees stated, "*first we needed to build the brand, and be known as a credible source...*".

To further improve the quality of its research findings and data, the Network created INDEPTH Working Groups as mechanisms for cross-site scientific work and quality assurance.⁵ Leadership of working groups is on a voluntary basis, though leaders have to be approved by the Board. The effectiveness of such groups depends on the effort by the leaders and whether or not the group manages to secure funding. In July 2013, the Network launched INDEPTHStats (an open website containing summary demographic indicators such as crude birth and death rates, age-specific fertility rates, under five mortality rates, as well some migration statistics) and the INDEPTH Data Repository which contains survey data from some of the sites. As of July 2014, the Repository had core data from 19 HDSS centers and one survey.

One of the functions of HDSS is to use the surveillance data to monitor trends in demographic events including mortality, fertility, and migration. While each HDSS provides core data and summary statistics annually on births, fertility, and migration, there is little by way of sophisticated demographic analyses. In addition, few papers use the longitudinal aspect of the data. While there are more than 3,100 papers in the INDEPTH Data Repository, few published papers have used the longitudinal feature of the demographic surveillance. The majority of the 'longitudinal' studies are clinical trials (out of 32 randomly selected publications from the repository, 21 were clinical trials, 1 was a longitudinal study that used the INDEPTH verbal autopsy tool to examine HIV mortality patterns over time, 7 were cross-sectional, and 3 were reviews). One of the initiatives that the Secretariat is using to encourage more use of the longitudinal surveillance data is to provide conference attendance funds for researchers who present papers that use such data at its biennial INDEPTH Scientific Conferences (ISC). At the 12th ISC in 2013, there were about 20 (out of about 80) papers and posters that used the longitudinal platform of the data and roughly about 28 papers that used trend analysis or cross-sectional methodology applied to data for multiple years. In contrast, at the 2007 ISC, only one or possibly two papers⁶ out of 25 used

⁴ Chandramohan D. et al. Should data from demographic surveillance systems be made more widely available to researchers? *PLoS Med*, 2008, 5(2): e57. See also, Walport M. and Brest P. Sharing research data to improve public health. *The Lancet*, 2011,12;377(9765):537-9; and Sankoh O. et al. Sharing research data to improve public health: a perspective from the global south. *The Lancet*, 2011, 378(9789):401-2

⁵ There are 15 INDEPTH Working Groups (WG), the most successful of which are the Malaria WG, which has generated over US\$35m of research funding; the Mortality WG which developed the INDEPTHStats; the INDEPTH Data System which has led to the Data Repository; and the Cause of Death WG which developed the verbal autopsy tool.

⁶ Unlike 2013, there is no online book of abstracts for earlier ISC conferences, so this assessment is based on the titles only.

longitudinal data from HDSS centers. The balance of topics being researched has shifted from demographic (and social issues) to mostly health. Less than 10% of the papers in 2013 were on non-health topics while in previous ISC there was a broader range of non-health topics (e.g. education, fertility, family planning, and migration)⁷. Overall, health funding is where most HDSS are getting their money. Thus, although there is a wealth of demographic data from the surveillance systems, HDSS centers have to prioritize funded research.

Mechanisms for Effective Communication

The Secretariat uses a range of tools and mechanisms for disseminating research to policy makers and other stakeholders. These include: newsletters (since 2011, four have been produced annually); policy briefs (ad hoc, so numbers vary from year to year); fact sheets (ad hoc); the website; social media (tweets, blogs, facebook); presentations at funders' forums; and presentations and booths at major conferences (e.g. IUSSP 2009, Population Association of America annual conferences, and the 6th African Population Conferences in 2012). Though the Secretariat has developed a Communications and External Relations Strategy, it was not clear if this is being implemented and monitored. At present, much of its interaction with international agencies such as WHO and media houses appears rather ad hoc than targeted and deliberate.

The Secretariat supports HDSS centers in effective communication by organising workshops for HDSS scientists on how to communicate research to policy makers and practitioners and how to use social media. Examples include, 'Communications Skills Workshop' for INDEPTH scientists in Thailand in 2009 and a similar workshop in Accra, 2011. In 2013, the Network corroborated with the African Population and Health Research Center in Nairobi to offer training on communication skills to a few sites. The Secretariat provides slides to help HDSS centers to represent the Network's activities and highlights accurately. An observation from several HDSS scientists was that such training was inadequate and often not followed up with further training and activities. This was confirmed by the Secretariat who reported that funding for such activities is limited, hence there is no follow-up.

Collaborations and Engagement with External Stakeholders

The Secretariat has plans to strengthen its *collaboration* with institutions whose core mission is policy engagement. Previous collaborations have been fruitful. Between 2012 and 2013, INDEPTH worked with the African Institute for Development Policy (AFIDEP) and the African Media and Malaria Research Network (AMMREN) to produce research and policy briefs on the Network's contribution to malaria research. Another example is a previous collaboration with the Institute for Development Studies (IDS), when together INDEPTH and IDS convened a seminar in Ghana on 'Enforcement of Reproductive Rights and Laws and Policies' (2008). A new collaborative partnership has been forged with the Population

⁷ It is difficult to work out the precise percentage of health to non-health papers in the absence of abstracts. However, based on titles, the percentage of papers that examined demographic (other than mortality) or other social issues was about 16% of the total substantive papers in 2007 and roughly 20% in 2009.

Council on a USAID-funded 'Evidence project' (2013-2015) to promote the use of evidence in scaling up quality family planning and reproductive programs.

On the global arena, senior members of the Network such as the Executive Director, Board of Trustees and members of the Scientific Advisory Committee (SAC) are often invited to take part in meetings with policy makers, funding agencies and prestigious research groups. Recent examples include: ED's address to the World Health Assembly (22 May 2014); a panellist at a symposium with Bill Gates at the Karolinska Institutet in Sweden (31st March 2014), presentations at the African Development Bank, the Heads of International Research Organisations' conference and many more. Such events are often communicated to the Network through the newsletter and on the website. The Secretariat also receives constant requests to collaborate with major global health institutes. The ED is supported by the Scientific Advisory Committee to analyse these requests.

Going forward, INDEPTH aims to use the re-launched *Research to Policy Working Group*. The group met for the first time in March 2014 in Accra, with physical representation from 7 centers. An activity plan was developed for 2014. This includes: a) identifying research outputs that have been influential in policy changes and practice; b) developing tools to support HDSS centers in their policy engagement work; c) identifying champions for policy engagement, and d) providing opportunities for peer-support and learning (e.g. through case studies). The group was kick-started with the help of a short-term consultant and the expectation is that when the Secretariat fills the post of a policy dialogue and communications specialist, the person will be the natural coordinator of this working group. Such a person would need to have knowledge of the international policy arena and be able to work effectively with the member centers.

What is the value placed on policy engagement work (relative to research) in the network?

According to Board members and staff at the Secretariat, translating research into policy and practice is highly valued but difficult to implement and quantify for a number of reasons which include:

- a) the difficulty of isolating INDEPTH's contribution when assessing collaborative ventures;
- b) activities are often ad hoc which makes evaluation hard;
- c) it is generally hard to estimate the impact of research on policies and practice; and
- d) the lack of staff capacity at HDSS centers and at the Secretariat to undertake policy engagement activities systematically.

The general consensus from members of the Board was that the amount of time spent on this activity relative to research was lower, probably about one-third. Some Board members acknowledged that more could be done, as one of them stated, "*this work [policy engagement] is valued, but we not where we want to be*".

By the nature of the network, most of its research activities are collaborative, either between HDSS centers or with external collaborators. As a rule of the thumb, where an activity involves three member

centers, it is considered as a network activity. Often the Secretariat is involved in brokering the collaboration and sometimes in securing funds. However, the role of the Secretariat is not always acknowledged in publications or dissemination. As one Board of trustees stated, *“we know that when we mention that we are members of INDEPTH, our chances of getting an award are high. Once we have the grant, we forget to acknowledge the Network and the Secretariat’s role”*.

Another observation is that because most HDSS centers have “parent institutions” who are based in the northern hemisphere, most of the dissemination events and press releases occur in those countries without acknowledgement of the role of the Secretariat. There is sometimes weak commitment by these northern partners to establish relationships with national or regional stakeholders, even when the research findings could benefit the local context much more than the international. As one staff from an HDSS center that we interviewed stated, *“My collaborators in the north issued a press release of our findings; the local stakeholders learnt about this through the internet”*.

Since the Secretariat currently does not have staff with adequate expertise in policy analysis and engagement, it often falls on the overstretched ED to lead on dissemination and policy engagement. There is, therefore, no formal follow-up or tracking of events and consequently, no evaluation.

How successful has the INDEPTH Network been in influencing policies and practice? At what level?

To answer these questions, we asked the Board and the Secretariat to make a self-assessment of their success in influencing policies and practice. We also asked Group 1 and Group 2 HDSS representatives to assess the role of the Secretariat in supporting HDSS centers to translate research into policies and practice. Finally, the Secretariat prepared two case studies as examples of their role in translating research into policy.

The general perception of the Board and Secretariat staff is that there are many network-level projects that are underway which have great potential of making an impact on policies and practice, but that it is too early to isolate specific policies and practices. In this review, we have excluded some highly publicized examples of research into policy which were started prior to the launch of the Network (e.g. the Navrongo Health Research Centre’s Community-based Health Planning and Services (CHPS) program and Ifakara Health Institute’s study on insecticide-treated bednets which led to the program being rolled out nationally). Some current examples of multi-site programs that are likely to have major global impact are the INDEPTH Effectiveness and Safety Studies of Antimalarials (INESS), from 2008, and the ‘Optimunise’ study, a vaccination and child survival project, 2011 to 2016.

A common observation among INDEPTH researchers and staff whom we interviewed was that the Secretariat was much better placed to engage with stakeholders at the international level rather than nationally. The challenge for the lean, Accra-based Secretariat to meaningfully engage with national policy makers (except perhaps in Ghana) was the reason for this view. It was felt that the Secretariat should continue to focus on *cross-cutting issues* such as cause of death, use of HDSS for vital registration, open data, and developing innovative methodologies for demographic surveillance and their analyses. The target for the Secretariat’s influencing strategy should be the regional and international policy arena

and the global academic community. Similar sentiments were expressed during interviews with HDSS staff, where there was recognition that the Secretariat could more ably present cross-site research findings, given its international networks. On developing methodologies, one senior HDSS scientist suggested that the Secretariat should focus more on “*developing software to help with data collection and harmonization of variables*”. A welcome initiative is that under the OpenHDS initiative, the Network is investing more than \$400,000 on developing tools for electronic data capture so that in future, the time between data collection and analysis may be shortened.

Impact Case Studies – the role of the Secretariat.

As a demonstration of the role of the Secretariat in facilitating the translation of research into policy and practice, the Secretariat generated two impact case studies. The first one, *‘Developing and validating a standardized Verbal Autopsy tool to elicit most probable cause of death for low- and middle-income countries’* demonstrates INDEPTH’s role in coordinating multi-site projects which have potential to significantly impact international and global policies and practices (see Box 1 for a summary and Appendix 3 for a fuller description). Clearly, for this type of project, findings from a single HDSS would not have such an impact. The researchers from the Secretariat who played important roles in leading and coordinating the verbal autopsy (VA) work were the current ED, Osman Sankoh, and the previous ED, Fred Binka. Later, the Secretariat co-opted Abraham Hodgson, who was the Director of Navrongo HDSS (now Director for Research at the Ghana Health Service) to be the INDEPTH representative on the INDEPTH-WHO committee. In 2012 the ED was invited to be a member of the core group of institutions that regularly discuss issues related to the strengthening of civil registration and vital statistics (CRVS) systems in African countries. This group is led by the United Nations Economic Commission for Africa.

1. INDEPTH SECRETARIAT CASE STUDY

Title: Developing and validating a standardized Verbal Autopsy tool to elicit most probable cause of death for low- and middle-income countries:

The INDEPTH Network, in collaboration with the World Health Organization, has developed a verbal autopsy (VA) tool for determining causes of death in settings where civil registration of vital statistics are incomplete or non-existent. This work has had significant global impact on national and international agencies, the global research community, and indirectly on millions of rural people who have been affected by the health policies influenced by this work. The VA tool has been particularly useful in rural areas of low- and middle-income countries (LMICs) where deaths occur in the absence of medically trained personnel or where clinical autopsies are not available. This has enabled better tracking of premature mortality and its causes in LMIC settings, and appropriate allocation of budgets towards diseases with the highest burdens. As this was the first tool developed by INDEPTH, the global impact of the VA tool confirmed the viability and usefulness of the Network’s coordination and HDSS platform for the development and of harmonized research tools for data collection. Other tools that were subsequently developed and are now being used by others include the INDEPTH Socioeconomic Status Tool and the INDEPTH Social Autopsy Tool.

The INDEPTH and WHO VA tool is perhaps the single most used product of the Network which has made an impact on practitioners and the research community. For example, the VA tool is used by WHO and UNICEF to report on causes of death and to track progress against diseases⁸. Furthermore high-impact publications such as the multi-agency publication, *Trends in Maternal Mortality 1990-2010*, and the Institute for Health Metrics and Evaluation's *Burden of Disease Estimates 2010*, have used statistics from the VA tool developed by WHO and INDEPTH. The VA tool, now also translated into French, is being used for research in routine civil registration and vital statistics systems.

The second impact case study, '*Integrating data from INDEPTH Network's Health and Demographic Surveillance System Centers and multiple household surveys to monitoring vital events in Kenya*' (Box 2), highlights very recent efforts by the Secretariat to bring together its member HDSS centers with national stakeholders. As a result, the full impacts are likely to be felt in years to come. The case study demonstrates the convening role of the Secretariat in bringing together several HDSS centers in Kenya with key government stakeholders to launch projects to understand demographic phenomenon and to test the feasibility of using the demographic surveillance system to improve coverage of registration of vital events. There are five HDSS centers in Kenya that are members of the Network, and together, they approached the Secretariat for support to facilitate a meeting with the National Bureau of Statistics. Two representatives from the Kenyan HDSS centers spoke very positively about the meeting which took place in Bellagio, Italy. A memorandum of understanding has been signed by the National Bureau of Statistics and the HDSS centers but it is too early to assess how this collaboration will pan out.

2. INDEPTH SECRETARIAT CASE STUDY

Title: Integrating data from INDEPTH Network's Health and Demographic Surveillance System Centers and multiple household surveys to monitoring vital events in Kenya.

The INDEPTH Network has enabled its member Health and Demographic Surveillance System (HDSS) centers in Kenya to work closely with four key ministries of the government to improve their understanding of mortality trends and patterns in the country and to explore the use of the INDEPTH demographic surveillance system as a tool for improving coverage of civil registration of vital events in rural settings. The Secretariat organized a workshop in 2012 in Bellagio, bringing together leaders of four HDSS centers based in Kenya (Kisumu, Kilifi, Mbite, and Nairobi) and representatives from the government of Kenya, led by the Director General of the Kenyan National Bureau of Statistics. A memorandum of understanding was reached and under this collaboration, a pilot study has commenced to institute vital registration systems based on existing surveillance structures in Kilifi and Kisumu HDSS as well as other interested HDSS. While it is too early to report population-level impacts, this collaboration has demonstrated that the HDSS is a viable platform for the Kenyan government to consider seriously support for civil registration of vital events.

⁸ Reports on causes of death by the World Health Organization and UNICEF rely on VA estimates for cause of deaths where registration of vital events is weak.

4. TRANSLATING RESEARCH INTO POLICY AND PRACTICE - Examples from HDSS Centers

Four HDSS centers were selected to provide examples of their work in translating research into policies or practice. As stated previously, the four centers were chosen using a number of criteria: those who had responded in the affirmative to a questionnaire sent by the Secretariat asking centers to report if they had impact on policies and practice in the past five years; to obtain a mix of centers, by age of HDSS; and geographical region. The centers were given a template to report on specific impact on policies or practice, the underpinning research, the role of collaborators and networks, including INDEPTH, and the source of funding for the research. Centers were also asked to provide names of stakeholder contacts who could verify the reported impacts. Finally, centers were asked about the positive factors that enabled them to translate research into policy and practice and what role the Secretariat should take in supporting HDSS centers.

All of the centers reported on findings which led to impacts on health policies and practice, demonstrating the health bias of the majority of HDSS. In all of the impact case studies, there was external funding for the research, and the Secretariat did not play a specific role in enabling the impact to happen other than the general support such as training on data collection and training HDSS staff.

Agincourt HDSS, South Africa

Hosted by the MRC/Wits Rural Public Health and Health Transitions Research Unit at the University of the Witwatersrand, the Center is situated 500 kilometres northeast of Johannesburg in the Bushbuckridge region of Mpumalanga province. The HDSS, which was established in 1992, is following a population of 110,000 people and data are updated annually. The Center's research investigates the dynamics of health, population and social transitions in rural South (and southern) Africa in order to provide evidence for more effective public health, public sector and social responses. The Center is supported by the University of the Witwatersrand and its research has multiple funders including the Wellcome Trust, South African and UK Medical Research Councils, and National Institutes of Health, to name a few.

In terms of publication, the Center is highly productive, averaging around 32 articles per annum in peer-reviewed international journals (including the Lancet, Bulletin of the World Health, International Journal of Epidemiology, and many more). Agincourt described the impact that they have had on policies to prevent hypertension and strokes in South Africa. Research from the HDSS demonstrated that the percentage of the adult population with hypertension in the Agincourt rural surveillance area was very high (43%) and that policies to reduce salt intake could save lives and reduce stroke-related morbidity (see Box 3 below and a full description in Appendix 3). As the impact case study claims, reduction in salt in manufactured food products in the country will have regional impact because of the export of manufactured food from South Africa to neighbouring countries.

3. AGINCOURT HDSS

Title: Influencing policies and practice to prevent hypertension and strokes in South Africa

With over a decade of research into blood pressure as an important facet of the rapid epidemiological transition in rural South and Southern Africa, the MRC/Wits-Agincourt Unit has influenced policies and practice at local, district, provincial and national levels. Sustained relationships with multiple stakeholders resulted in responses with potential for major public health impact. Research since 2002/3 demonstrated that about 43% of the Agincourt population had hypertension, that reducing the sodium content of bread would reduce population-wide systolic blood pressure nationally, and prevent about 2000 fatal and 2300 non-fatal strokes annually, and that in addition to salt, smoking and obesity were critical risk factors for strokes. The research led to: development of national stroke prevention initiatives; changes in national policy regarding salt content in foods; and research into health system interventions for integrated chronic disease management in partnership with the Ministry of Health.

The success of the Agincourt HDSS in influencing policies and practice can be attributed to the quality of the research and its policy-relevance, and the trusted relationships that the researchers have with users of research. Evidence of the quality of the research findings is endorsed by their publication in high quality journals (for example The Lancet). The stakeholders that we contacted commented on the high quality of the research at Agincourt, describing it as *“outstanding”*. The Agincourt case study is a good example which demonstrates that the process from research to policy engagement to impact is not linear. In one of the examples of impact in the case study, the stakeholder initiated the interaction after reading about the research in the newspapers. In another case, after the initial research, the stakeholders requested Agincourt to conduct additional research to strengthen the case for change in legislation. As one of the stakeholders stated, *“Firstly we looked at research that was already being produced (such as high rates of strokes and other NCDs in this area) and this informed our policy directions to do more about reducing hypertension related mortality and morbidity. We then requested further research be done in order to get more information (of a slightly different kind) to move forward. This contributed significantly to policy and legislative initiatives to reduce hypertension - salt reduction being one such important initiative”*.

The Center’s dissemination strategy is very effective. As one of the stakeholders stated, *“While journal articles are important, policy makers often don’t have the time to read them. Personal communication and interaction as well as presentation of data have been very important ways in which scientific data has been communicated to us from Agincourt. They have also summarised data for our perusal”*.

Staff at Agincourt attributed the successful translation of research into policy and practice to the following:

- The presence of a stable and productive research unit, with its commitment to community engagement and high quality research.

- A unit dedicated to Learning, Information Dissemination and Networking with Communities has been integral to the ability of the Agincourt HDSS to successfully translate research into policy and practice. The unit has experienced and dedicated staff who work with principal investigators to ensure that the policy relevance of their research is explored and pursued, that information is disseminated to community groups, government departments and non-governmental organizations.
- Inclusion of cost-effectiveness studies as a core part of intervention research. This is popular with policy makers, especially estimates of lives saved.
- Sustained relationships with policy makers and implementers and production of factsheets at the end of each study ensure a reciprocal, sustained relationship with policy makers and service providers.

Dodowa HDSS, Ghana

The Dodowa HDSS is run by the Dodowa Health Research Centre (DHRC) in Ghana and is situated in the Dangme West District, one of the districts in the Greater Accra region. The HDSS, which was launched in 2005, is following up a rural population of nearly 112,000. Data are updated twice a year. Dodowa is one of three research centers that were instituted by the Ghana Health Service (GHS), (the others are Navrongo and Kintampo). As a government owned center, its core staff are paid by GHS which also provides some funding for infrastructure and utility bills. Research costs are mostly externally sourced, except when the government needs the centers to conduct specific piece of research in which case they provide funding. Both staff and stakeholders admit that the core funding is inadequate; one of the stakeholders informed us that GHS is supposed to spend 5% of its budget on research but the actual fraction is far less than this. Nevertheless, the Center appears to be successful in securing external funding (some of the current and previous funders include the Wellcome Trust, WHO/Tropical Diseases Research program, Gates Foundation and Grameen Foundation).

DHRC described the impact that their research has had on policies for home management of fevers in children under the age of five years in Ghana (see Box 4 for a summary and Appendix 3 for impact case study). The example demonstrates that negative findings can be just as useful in informing policies and practice. In the case of Dodowa, their research demonstrated that the existing strategy for home management of fevers among children using antimalarials only was just as effective as antimalarials plus antibiotics, except when there were respiratory signs of pneumonia, in which case antibiotics should be prescribed. The results confirmed to health policy makers in the country to continue with the existing strategy for home management of fevers in children.

DHRC has been successful in translating research into national policy and practice since its conception. The fact that it was created by GHS and its proximity to Accra could have been contributory factors. One stakeholder gave another example of successful research-to-policy work conducted by Dodowa which was to assess the feasibility of introducing a health insurance scheme in rural communities. Researchers at the DHRC disseminate their research at different levels: district, regional and national annual meetings, thus ensuring that the research is accessible to many stakeholders. The Center's senior staff

also hold regular informal meetings with officers at GHS and the Ministry of Health, and these are used for conceptualizing research as well as reporting of results. The roles of researcher and policy maker are often interchangeable between the Ghanaian HDSS centers and GHS (researchers can get posted to a research center or to GHS), which means that there is greater understanding of research and of policy-making for all parties.

4. DODOWA HDSS

Title: Improving policies for home management of fevers in children under-five years in Ghana

Research conducted at the Dodowa Health Research Centre (DHRC) has influenced the Government of Ghana's health policy on the home management of fevers among under-five children. The research conducted between 2007 and 2009 in Dangme West district showed that using antimalarial only for home management of fevers was just as effective in reducing under-five mortality as using antimalarial plus antibiotics. Furthermore, the results showed that the home-based management of fevers with antimalarial only was more cost-effective than antimalarial plus antibiotics. These findings provided evidence for continuation of the existing national strategy in home management of fevers among children using antimalarial only for fevers and to prescribe antibiotics only when there are respiratory signs of pneumonia.

Another important observation from discussions with the stakeholders at GHS is that researchers at Dodowa Health Research Centre are trusted. In addition, DHRC has a staff member who, as well as doing research, supports the policy engagement work⁹ of DHRC enabling it to understand who their important stakeholders are, how best to disseminate findings to stakeholders, and which research is having policy impact.

In summary, Dodowa HDSS appears to be having an impact on policies in Ghana. The enabling factors were: policy-relevant research, the key role played by the government in the activities of the HDSS, and the political capital and level of trust among stakeholders in Ghana that the researchers have. The presence of staff with knowledge of policy engagement has benefitted the Center in understanding how to influence stakeholders.

Manhiça HDSS, Mozambique

The HDSS is run by Manhiça Health Research Centre (CISM) and was established in 1996 in a rural area of southern Mozambique with funding from the Spanish Agency for International Development and Cooperation. The HDSS currently follows around 90,000 individuals living in approximately 20,000 enumerated and geo-positioned households. There are 6 data rounds per year. The Center's main research focus is to use demographic and clinical data to understand priority health issues. CISM initially started by conducting socio-demographic observational studies to describe patterns and trends of

⁹ Dr Escribano completed a Dr PH dissertation on policy analysis at the London School of Hygiene and Tropical Medicine. She used Dodowa as a case study.

fertility, migration, morbidity, and mortality in the area. CISM has now widened its scope to include more in-depth molecular, immunological, and entomological studies, as well as clinical trials and the evaluation of interventions. The Center is very active in terms of research publications. In the past three years, the average number of publications per annum in international peer-reviewed journals was about 27 (including publications in the Lancet, New England Journal of Medicine, American Journal of Tropical Medicine and Hygiene, and Internal Journal of Epidemiology).

Manhiça described the impact that their research has made on policies to introduce vaccinations in the country against pneumonia diseases (see Box 5, and Appendix 3). The research demonstrated the high burden of pneumonia diseases among under five children which led to the government's decision to introduce the Haemophilus Influenzae type B (Hib) vaccine in the country in 2009. Similarly, after research from the HDSS demonstrated that the Pneumococcal Conjugate vaccine significantly improved child survival, the vaccine was rolled out throughout the country in 2013.

5. MANHIÇA HDSS

Title: Influence on pneumonia vaccine policies in Mozambique

The Manhiça Health Research Centre (CISM) has played a major role in generating knowledge for fighting against prevalent diseases in Mozambique and the region. Studies conducted by the CISM have guided the health authorities and decision-making bodies to define or adjust health policies. Specifically, research conducted by CISM in 2009 demonstrated the high burden of pneumonia among children in Mozambique, showing high incidence of 416/100,000 child-year at risk (reaching 779/100,000 in children under 3 months of age), with a case fatality rate of 10%. These findings prompted the government to request assistance from the GAVI Alliance in 2009 to introduce the Haemophilus Influenzae type B (Hib). Using the HDSS platform, the center monitored pneumonia cases among children and showed that among children under 1 year and 5 years of age, significant reductions occurred in the rates of invasive Hib disease (91% and 85%, respectively) after vaccination, and for very severe pneumonia, the reductions were 29% and 34%, respectively. Similarly, research by CISM which demonstrated the benefit of the Pneumococcal Conjugate vaccine prompted its roll-out in the country in 2013.

The political capital enjoyed by the center was confirmed by the award in 2014 of a prestigious medal (Bagamoyo medal) by the president of the country. The collaboration with Spanish institutions, especially Barcelona Institute of Global Health, is highly valued by both countries and has led to many collaborative peer-reviewed publications in high impact journals. Dignitaries from Spain regularly visit the Center (e.g. Spanish parliamentarians and the Queen of Spain in 2013). Since the Center receives funding from the government, there is interest among the researchers to produce policy-relevant research, and among the policy makers to use the findings of the research. Unfortunately we did not get a response to our request for interview from the stakeholders in Mozambique. Thus, we are unable to report on the perception of the quality of research and its relevance from an end-user perspective.

Nairobi HDSS, Kenya

The Nairobi HDSS is an urban surveillance system which was set up in 2000 by the African Population and Health Research Center (APHRC). It is following nearly 62,000 people in two informal settlements in the city of Nairobi to investigate the linkages between urbanization, poverty, and health. APHRC was set up with a grant from the Population Council, and became autonomous in 2001. Unlike many other HDSS centers, Nairobi does not have a parent university or research institution in the northern hemisphere nor does it belong to a government department. APHRC's major sources of funding are the Wellcome Trust, the William and Flora Hewlett, David and Lucille Packard, and Bill and Melinda Gates Foundations, Sida and IDRC (Canada). In 2013, the Center produced 44 articles in international journals including the Lancet, International Perspectives on Sexual and Reproductive Health and BMC Public Health.

The Nairobi HDSS described the impact of their research on cardio vascular diseases (CVD) in two informal settlements. The research showed, for the first time, the high prevalence of risk factors such as overweight and obesity, and hypertension among adults. This prompted the Nairobi City Council to set up clinics for screening and management of CVD. Furthermore, the community reacted by setting up community based organizations to manage a drug revolving fund for the treatment of CVD.

6. NAIROBI URBAN HDSS (NUHDSS)

Title: Cardio Vascular Disease (CVD) risk factor assessment study

The Cardio Vascular Disease (CVD) study conducted by the African Population and Health Research Center (APHRC) led to the decision by the City Council of Nairobi (CCN) to prioritize CVD management in its primary health care facilities. Findings showed high prevalence of overweight and obesity particularly among females (43%) in the two slums of the Nairobi Urban HDSS, and hypertension and diabetes age-standardised prevalence of 18.4% and 5.4%, respectively, among adults aged 18+ years, (37% and 11% among older adults aged 50+, respectively). As a result, the CCN established 10 clinics through the rapid results initiative. To date, there are at least six active CVD clinics in CCN health facilities. Two patient support groups were registered as Community Based Organizations in the two NUHDSS slums, with members contributing monthly to a drug revolving fund, entitling them to treatment and a month's supply of drugs. The clinics are each handling about 200 patients every month and all newly diagnosed patients are enrolled in the support groups.

A particular feature of APHRC is the presence of a policy engagement and communications unit, with clearly defined objectives for policy engagement, knowledge management, and communications. The effectiveness of APHRC's approach to policy engagement was confirmed by one stakeholder whom we interviewed who commented on the "*professionalism*" of the team at APHRC, and of the researcher-end-user relationship which was a two-way process. The quality of the research was also viewed by the stakeholder "*as excellent*", and this is further endorsed by acceptance of APHRC's papers in peer-reviewed journals and invitations to present at major conferences. A second stakeholder whom we contacted did not respond.

The Center attributed the success of their efforts in translating research into policy on the following:

- Conducting research on issues that are relevant to the local context.
- Having a standalone division that is in charge of policy engagement and communication, working with researchers to engage with policy makers through various channels. Building capacity of researchers to communicate evidence sensitively and appropriately with policy makers.
- Partnership with key government bodies such as Nairobi City Council (now Nairobi County) and relevant government ministries (e.g. Ministry of Health, Ministry of Education).
- Building cordial and sustained relationships with key government officials and nurturing these bi-directional relationships which also include participation of our researchers in government committees/task forces and their involvement on some research projects.
- Involvement of key stakeholders throughout the research process (planning, design, implementation, dissemination) to increase ownership of the research outputs.

5. BARRIERS TO TRANSLATING RESEARCH INTO POLICY – Evidence from HDSS Centers

As part of this review, we contacted the leaders of four HDSS centers to find out the experience of their HDSS in translating research into policy and what barriers they faced. Center leaders were based in the countries where the HDSS were located but they were not necessarily the directors of the HDSS centers nor the PIs. The centers were: Farafenni in the Gambia, Nouna in Burkina Faso, Iganga/Mayuge in Uganda, and Kilite Awlaelo in Ethiopia. We were unable to establish contact with the Ethiopian-based HDSS.

Description of the three centers

Farafenni HDSS. This is located approximately 170 km from the coast in a rural Gambian district north of the River Gambia. It was set up in 1981 to generate demographic and health information required for the evaluation of a village-based primary health care program in 40 villages. With regular updates of demographic events and residency status, the surveillance area was extended in 2002 to include Farafenni Town and surrounding villages to support randomized control trials. With over three decades of prospective surveillance, Farafenni is one of the oldest HDSS in the INDEPTH Network. The HDSS has over three decades worth of data, following about 48,000 individuals. Currently, data are updated 3 times per year. Its current portfolio is to track Millennium Development Goal 4 attainment in rural Gambia. The Center is funded by the Medical Research Center (MRC), the Gambia, which is in turn funded by the UK MRC.

Nouna HDSS. The HDSS was started in 1992, initially as a health research project linked to the district. In 1999, the research project became a research center, after a positive evaluation of the research activities. The Center is linked to the Ministry of Health, which provides some financial support to the Center. The size of the population that is under surveillance is around 93,000, and data are updated 3

times per year. The main aim of the Center is “to provide research for interventions and policies”. Nouna’s main research partner is the University of Heidelberg in Germany, who pays salaries for some of the research staff at the Center from funds provided by the German Cooperation.

Iganga/Mayuge HDSS. The HDSS- was established in August 2004. It is located in the eastern part of Uganda, approximately 115km from Kampala city. The population under surveillance is approximately 80,000 people, with about 80% living in rural areas and 20% peri-urban areas. Data are updated 2 times in a year. The main objectives of the HDSS are: a) to develop operational research capacity for Makerere University staff and graduate students; b) to provide a platform for high quality household survey data for operational field trials of health, agriculture, socio-economic, veterinary and technological interventions in rural and peri urban populations; c) and to contribute to the development of the new sentinel surveillance system by providing unique, essential, household level information individually tailored for policy, planning and research needs. The HDSS is a partnership between Makerere University and Karolinska Institutet in Sweden.

Key Findings

Production of High Quality Research

From interviews and website information, the production of high quality research of publishable quality is not problematic. All of the three HDSS listed above are publishing in international peer-reviewed journals. Most of the papers are collaborative with researchers in “parent institutions” in the northern hemisphere. The collaborators in the northern hemisphere appear more proactive in putting up lists of publications from the HDSS on their websites. The majority of the published papers (more than 70%) by HDSS are health-related, and very few papers actually use the longitudinal feature of the demographic surveillance data. Although these HDSS centers have generated years of data from the surveillance system, these data are under-utilized in part because the centers are funded to do specific topics in health research. There was a concern about the sustainability of the surveillance system, with some of them only guaranteed 2-3 years of funding. This was also a concern raised by the Secretariat.

Positive Factors and Barriers to Policy Engagement

Dissemination of research to the local community is often part of a successful surveillance system, and most HDSS centers do this. HDSS centers conduct mobilization events to introduce projects and to facilitate acceptance of the project among the community. A number of HDSS centers work with theatre groups to dramatize the messages and to create interactive sessions. These local dissemination and community activities appear to be popular.

How successful HDSS centers are in engaging regional and national policy makers appears to be dependent on a number of factors including the commitment of the parent institution to policy engagement in the country, the demand for evidence from the stakeholders, and the presence of staff

with skills in communicating research to end-users. Centers with parent institutions in the northern hemisphere tended to emphasise dissemination to an international audience. It was not unusual for press releases of important research findings to be prepared and disseminated in the northern hemisphere, with little input from researchers in the south.

Another perception from HDSS staff was that some center PIs and directors were more concerned with influencing the scientific community than with policy makers. This meant that scientific papers and conference presentations were seen as the ultimate dissemination tools. In addition, there was lack of skills among local HDSS staff in appropriate communication and policy engagement. Though the Secretariat had facilitated some workshops on communication skills for scientists, these were seen to be “*inadequate*”. As a result, most scientists expected stakeholders to pick up research findings and policy recommendations from scientific publications. As one of the interviewees stated, “*The way we are reporting to them is not ideal for them to absorb our research*”. There was also an acknowledgement that most research funding did not include activities for long-term impact activities.

The lag time between research production and uptake by policy makers and practitioners was acknowledged, and though not a barrier in itself, was seen as a challenge in tracking efforts. The HDSS scientists also perceived that the stakeholders had low demand for research evidence. Thus, even at centers that were run by government entities, there was not sufficient interaction with the stakeholders to understand what they needed in terms of evidence.

What can the Secretariat do to support HDSS?

We asked this question to staff at all the seven HDSS that we interacted with. The most common response to this question was “*training in communication skills*”, and also “*support with developing materials for policy engagement*”. It was highlighted that 2-3 day workshops every few years were not sufficient. Another suggestion was that the Secretariat could play a brokering role by encouraging networking between HDSS for peer-learning and linking policy makers with scientists. The Secretariat has started doing this already as was seen from its second impact case study. Another suggestion was placement of students interested in policy engagement at HDSS centers so that the skills of the next generation are also strengthened.

In conclusion, most of the HDSS centers appear to be producing high quality research that can be translated into policy and practice. The majority of the research is on health topics and clinical trials, since this is where most centers were getting their funding. The success or otherwise of translating research into policy and practice were dependent on a number of factors including the commitment of the parent institution to policy engagement with the local stakeholders and skills in effective communication among HDSS center staff.

6. CHALLENGES AND RECOMMENDATIONS

6.1 At a deeper level, a key challenge for the INDEPTH Network is to identify and address research and policy questions for which the unique longitudinal and multi-dimensional platform of the HDSS (which

also makes it very expensive) is utilized as an indispensable component. Several of the impact case studies that we assessed are based on research projects that could have also been gained from much simpler research designs (e.g. interventions to reduce prevalence of certain diseases). This is in part due to the nature of funding which is biased at the moment towards specific health related projects that do not utilize the full potential of the HDSS setting including its extensive demographic components.

Recommendation: In addition to being responsive to specific donor driven and mostly exclusively health-related projects, the INDEPTH Network and its funders should invest in the conceptualization of directly policy relevant research questions that optimally utilize the great capabilities of the longitudinal and multi-dimensional HDSS platform. One example for such an effort could be the highly policy relevant study of the interactions between health, education and fertility and the micro and community level. While the scientific literature suggests that these three factors are greatly interconnected (with effects going in all directions) the empirical assessment of these has been hindered by the need for a complex longitudinal and multi-context study design of precisely the sort that HDSS offers. Another example is unpacking the causal linkage between reproductive health and women's economic empowerment. New insights on the nature of these interactions would be of highest policy relevance, from the global level Sustainable Development Goals down to the design of community- level health and education services.

6.2 Another challenge that the Secretariat faces in coordinating and leading network-level work on translating research into policy and practice is the lack of staff at the Secretariat with appropriate skills of policy engagement. While funding is one part of the problem, the Secretariat has been trying unsuccessfully to recruit a senior policy and communications analyst.

Recommendation: The Network should widen and intensify its efforts to recruit a policy dialogue and communication specialist to support the Executive Director in coordinating the policy engagement work of the Network. This person should have knowledge of the international policy arena. While it is desirable that the person is based at the Secretariat, another option might be to recruit one or two experienced people from HDSS centers on a part-time basis.

6.3 The Network does not have a clearly defined strategy for policy engagement, and as a result, most of the activities in this area are ad hoc making it difficult to track impacts. Specifically, the Network has not yet identified and mapped the primary stakeholders it wishes to influence, nor how to proactively communicate and engage with them. In 2009, the Network developed a Communications and External Relations Strategy (CERS), which is a useful component of a Policy Engagement Strategy, but it is not clear if the CERS is being implemented or monitored. There has been limited interaction with global high-profile bodies (e.g. World Economic Forum) and while contact has been established with major regional bodies in Africa and Asia (e.g. NEPAD/African Union, Asian Development Bank, African Development Bank), there is potential for INDEPTH to do more to influence these stakeholders.

We recommend that the Network should develop a policy engagement strategy which clearly identifies the potential stakeholders and beneficiaries of INDEPTH's products, what activities are necessary to ensure that there is impact, and an evaluation plan. In identifying its stakeholders, the Network may want consider mapping stakeholders (e.g. funders, policy actors, media, civil society, academic

community and so on) and it should develop action plans to engage with each group. On policy actors, INDEPTH should look beyond WHO and ministries of health.

We further recommend that the Network should review its Communications and External Relations Strategy to align it with the Network's revised strategic objectives. There should be clarity between the actions that are being led by the Secretariat and those led by center members. Annual action plans would be a useful way of managing the implementation of the strategy.

At the national level, we see the role of the Secretariat as being strategic but in the background, supporting the HDSS centers. At the international level, the Secretariat should play a lead role in targeted and direct engagement with the international policy and donor community.

6.4. A distinction between HDSS centers that are more successful in policy engagement and those less engaged is that the former use a proactive approach to policy engagement, with strong links with the stakeholder beneficiaries. HDSS that develop trusted relationships with end-users of research are more likely to be successful in translating research into policy and practice. Where researchers are trusted, the relationship can be bi-directional, with stakeholders sometimes making the first move.

We recommend that HDSS centers that have not yet developed policy engagement strategies should be encouraged to do so, being clear of the audience they wish to influence and developing trusted relationships with stakeholders.

6.5 With regards to publications from HDSS centers, the "INDEPTH" brand is not highly visible. Although the INDEPTH Data Repository has citation information for more than 3,000 journal publications published by researchers affiliated to HDSS centers, the majority of these do not mention their affiliation to INDEPTH. In contrast, researchers often acknowledge their connection to the Network when applying for grants as there is a perception that this enhances the chances of success.

Since research findings from HDSS centers published in peer-reviewed journals are a key outlet that has the potential to influence the international state of the art, we recommend that efforts should be made to increase the visibility of INDEPTH in the publication and dissemination of such findings. It may be a promising idea to occasionally publish (in the form of reprints or summaries of findings) a bundle of such scientifically influential studies and distribute them under the INDEPTH logo.

We also recommend that the Secretariat should identify key "cross-cutting products" that it can spearhead in dissemination for policy translation. Repeatedly, the "cause of death" work was mentioned as one such example that the Secretariat should focus on.

6.6. Recently, the Network has launched the INDEPTH DATA Repository and INDEPTHStats which have the potential to increase utilization of the data by the wider research community.

We recommend that efforts should continue to make more surveys and more standardized variables available so that over time this could become one of the standard references for international comparative studies. Investments in software to reduce the time between data collection and analysis could reap huge rewards. We recognize that dealing with longitudinal data is more challenging than for

example, the widely used IPUMS and DHS databases, but ultimately it must be the goal to make as much INDEPTH data as possible available to the international research community in order for it to become a significant resource for international policymaking.

6.7. Funding for research usually ends with data collection or publication of findings in journals without any funding for impact activities. Also, because of the lag time between the end of a project and realization of impact, there is often no money left for policy engagement activities.

Our recommendation to the Network is to ensure that project costings include budget lines for policy engagement and impact-related activities. Periodically, the Secretariat could apply for follow-on funding to “mine” INDEPTH’s research for policy engagement and societal impact. Examples of such opportunities include the Wellcome Trust International Public Engagement grants and grants for systematic reviews.

APPENDIX 1: Terms of Reference

The objective of this consultancy is to determine the conditions that must be met for HDSS in SSA to have policy relevance and how the INDEPTH Secretariat supports member centers that run HDSS to achieve this goal. Questions to be answered include:

- a) To what extent do HDSS run by INDEPTH member centers function as robust research platforms? Are there indications that the evidence they produced are taken up in policy formulation?
- b) Which HDSS have been successful in this regard? What communication strategies and formats did these sites use to convey policy and program relevant findings to stakeholders?
- c) What factors are associated with HDSS success in terms of contributing to science and engaging in local and national policy-making?
- d) How does the Secretariat support high performing sites (i.e., those that generate evidence that guides policy-making)? In other words, what is the value-added of these HDSS participation in INDEPTH? (Refer to list of important contributions HDSS have the potential to make and INDEPTH strategic objectives on Page 1.) I did not notice a list on p.1 which matches this description
- e) What barriers to success can the Secretariat realistically address for HDSS that are not achieving their potential?
- f) What factors positively and negatively influence the Secretariat's ability to support HDSS (possibilities to explore include, but are not limited, to staffing and cost structures)?
- g) How does the Secretariat itself engage with stakeholders outside of the Network such as policy makers, researchers outside of the INDEPTH Network and donors based on the work of HDSS? To what extent has the Secretariat been successful in these engagements?

APPENDIX 2 – Table 2 Profile of African HDSS and Responses to Short Survey

Center name	Site name	Country	Year established	Year became a member	Affiliation	Size of population
Africa Center	Africa Centre Demographic Information System	South Africa	1998	1999	University of KwaZulu-Natal & Wellcome Trust	93,540
MRC/Wits Rural Public Health & Health Transitions Research Unit	Agincourt	South Africa	1992	1998	University of Witwatersrand	110,000
Bandim Health Project	Bandim	Guinea Bissau	1978	1998	National Institute of Health & Statens Serum Instut, Copenhagen	105,000
Institut de Recherche pour le Developpement (IRD)	Bandafassi	Senegal	1970	2001	Institut de Recherche pour le Developpement	13,000
IRD	Mlomp	Senegal	1985	2001	Institut de Recherche pour le Developpement	8,200
IRD	Niakhar	Senegal	1962	1999	Institut de Recherche pour le Developpement	43,000
Butajira Rural Health Program	Butajira	Ethiopia	1987	1999	Addis Ababa University & Umeå University	74,400
Dabat Research Center	Dabat	Ethiopia	1996	2013	University of Gondar	46,984
Dikgale	Dikgale	South Africa	1995	1998	University of Limpopo (Turfloop Campus)	35,000
Dodowa Health Research Centre	Dodowa	Ghana	1998	2005	Ghana Health Service (MoH)	111,976
MRC The Gambia	Farafenni	Gambia	1981	2010	Medical Research Council (UK), The Gambia;	47,331
Institute of Health Sciences Research, Jimma University	Gigel Gibe	Ethiopia	2005	2012	Institute of Health Sciences Research, Jimma University	
Ifakara Health Institute	Ifakara	Tanzania	1996	1998	Autonomous	161,000
Ifakara Health Institute	Rufiji	Tanzania	1998	1998	Tanzania Essential Health Intervention Project, Ministry of	97,000

					Health	
Karonga Prevention Study	Karonga	Malawi	2002	2003	London School of Hygiene & Tropical Medicine	35,730
Kaya	Kaya	Burkina Faso	2007	2010	Institut de recherche en Sciences de la Santé/Centre National de la recherche Scientifique & Ministry of Higher Education & Research	64,480
Institute of Public Health, Makerere University	Iganga / Mayuge	Uganda	2004	2005	Makerere University & Karolinska Institutet in Sweden	79,794
KEMRI Wellcome Trust Research Programme, Kilifi	Kilifi	Kenya	2001	2005	Kenya Medical Research Institute & University of Oxford	260,000
Kersa Demographic surveillance and Health Research Center (KDS-HRC)	Kersa	Ethiopia	2007	2013	Haramaya University	52,480
Mekelle University	Kilite Awlaelo	Ethiopia	2009	2012	CDC/European Public Health Alliance and Mekelle University	65,848
Ghana Health Service	Kintampo	Ghana	2003	2004	Ghana Health Service, MoH	142,977
KEMRI/CDC	Kisumu	Kenya	1992	1998	Kenya Medical Research Institute and CDC	230,000
KEMRI	Kombewa	Kenya	2007	2013	Kenya Medical Research Institute	123,456
Manhica Health Research Centre	Manhica	Mozambique	1996	1998	National Institute of Health Clinic/ Barcelona Institute for Global Health	89,617
Tanzania and Netherlands Support Program, MOH	Magu	Tanzania	1994	2001	National Institute for Medical Research	35,000
KEMRI/Nagasaki University	Mbita	Kenya	2006	2010	Institute of Tropical Medicine Japan/ Kenya Medical Research Institute/ Spring of Hope Project	54,014
African Population and Health Research Center	Nairobi	Kenya	2002	2001	Autonomous	61,695

Nahuche	Nahuche	Nigeria	2009	2012	Ministry of Health, PRRINN-MNCH Program	136,106
Centre Muraz / Ministry of Health	Nanoro	Burkina Faso	2009	2010	Ministry of Health and IRSS from the Ministry of research)	61,632
Navrongo Health Research Centre	Navrongo	Ghana	1993	1998	Ghana Health Service	156,735
Centre de Recherche en Sante de Nouna	Nouna	Burkina-Faso	1992	1998	Ministry of Public Health & University of Heidelberg	93,000
Ouagadougou	Ouagadougou	Burkina Faso	1998	2002	Ministry of Public Health and	82,387
Rakai	Rakai	Uganda	1988	1999	MoH, Makerere, Columbia & Johns Hopkins Universities	50,000
Centre National de Recherche et de Formation Surle Paludisme (CNREP)	Sapone	Burkina Faso	2005	2009	MoH	86,089
CSRS	Taabo	Cote d'Ivoire	2009	2012	Centre Suisse de Recherches Scientifiques	38,478
UK MRC	West Kiang	Gambia	2005	2010	UK Medical Research Council	14,364

APPENDIX THREE

Impact Case Study 1

NAME OF HDSS COORDINATING CENTER:	INDEPTH Network Secretariat
TITLE OF IMPACT CASE STUDY:	Developing and validating a standardized Verbal Autopsy tool to elicit most probable cause of death for low- and middle-income countries
CONTACT DETAILS:	Osman.Sankoh@indepth-network.org 38 & 40 Mensah Wood Street, East Legon P.O. Box KD213 Kanda Accra, Ghana
1. Summary of the impact	
<p>The INDEPTH Network, in collaboration with the World Health Organization, has developed a verbal autopsy (VA) tool for determining causes of death in settings where civil registration of vital statistics are incomplete or non-existent. This work has had significant global impact on national and international agencies, the global research community, and indirectly on millions of rural people who have been affected by the health policies influenced by this work. The VA tool has been particularly useful in rural areas of low- and middle-income countries (LMICs) where deaths occur in the absence of medically trained personnel or where clinical autopsies are not available. This has enabled better tracking of premature mortality and its causes in LMIC settings, and appropriate allocation of budgets towards diseases with the highest burdens.</p> <p>As this was the first tool developed by INDEPTH, the global impact of the VA tool confirmed the viability and usefulness of the Network’s coordination and HDSS platform for the development and of harmonized research tools for data collection. Other tools that were subsequently developed and are now being used by others include the INDEPTH Socioeconomic Status Tool and the INDEPTH Social Autopsy Tool.</p>	
2. The underpinning research	
<p>Many low- and middle-income countries are unable to determine the causes of deaths that occur in their population and this problem is most acute in rural areas where deaths occur at home and burials of the deceased happen without medical certification or clinical autopsies. Determining the cause of death is a core demographic surveillance activity but over time many different questionnaires were being used by members of the Network so that it was necessary to harmonize the methods for comparability and quality control. From the early 2000s, the INDEPTH Network in collaboration with WHO developed a questionnaire, named the Verbal Autopsy (VA) tool, which is used by trained field works to elicit the most probable cause of death. The completed questionnaire is independently assessed by two physicians and using the International Classification of Disease codes, the most probable cause of death is determined if there is agreement between them. Where there is no agreement, a third physician assesses the information. A cause of death is given if the third physician agrees with one of the first two causes given; otherwise the cause is given as undetermined. The original tool, which was published on the INDEPTH website in 2003, was intended for use in research settings hence it is a very long, covering many diseases most common in different life stages (e.g. child, maternal, adolescent, adult and old-age deaths). The VA tool was validated in several Health and Demographic Surveillance System centers in mid to late 2000s.</p> <p>INDEPTH set up the Cause of Death Determination Working Group to spearhead the development and validation of the tools. To enable as wide consultation and collaboration as possible, the Secretariat and WHO have been organizing international workshops with the participation of experts from INDEPTH member centers and the global scientific community.</p>	

In order to be able to use the tool for many deaths as in a national scale, there was need to shorten the research questionnaire. INDEPTH and WHO, with other partners, embarked on a study between 2011 and 2013 to shorten, simplify and standardize the verbal autopsy (VA) so that it could be applied on a larger scale such as routine civil registration and vital statistics systems. The study involved reviewing the existing VA instruments, revising the cause of death (CoD) list and the reduction of the interview time by about 40%.

Members of the Secretariat, namely Fred Binka and Osman Sankoh, played key roles in scientific leaderships of this work. The development of the verbal autopsy is continuing, and members of INDEPTH who are on the WHO Taskforce are Osman Sankoh, Peter Byass (Chair of SAC), and Sam Clark (member of SAC).

References

1. The VA tool in English and French on the INDEPTH website:
http://www.indepth-network.org/core_documents/
2. <http://www.globalhealthaction.net/index.php.gha/article/view/21518>
Citation: Global Health Action 2013, 6: 21518 – <http://dx.doi.org/10.3402/gha.v6i0.21518>
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4. Kahn et al (2000). Validation and application of verbal autopsies in a rural area of South Africa. *TMIH* 5 (11), 824-341
5. Yang et al (2005). Validation of verbal autopsy procedures for adult deaths in China. *IJE* 35 (3), 41-748
6. Chandramohan et al (2007). Verbal autopsies for adult deaths: their development and validation in a multicenter study. *TMIH* DOI: 10.1046/j.1365-3156.1998.00255.x

3. Details of the impact

INDEPTH research on the VA tool attracted WHO to become partners in its development and as a result, the potential for global influence was created from the outset. The INDEPTH VA tool is used in numerous low- and middle-income countries, especially where civil registration of vital statistics is non-existent or weak. All the 20 countries in Africa, Asia and Oceania where HDSSs operate now use the INDEPTH/WHO verbal autopsy tool. In South Africa, for instance, the most recent census introduced the use of VAs on a sample of deaths to determine causes. In India and Tanzania, a nationally representative program is being implemented, called Sample Vital Registration with Verbal Autopsy.

The VA and data generated from it are also being used by national agencies, international organizations including World Health Organization and UNICEF, and researchers globally to determine cause-specific mortality and the burden of diseases. For example, the World Health Organization used the INDEPTH data on causes of deaths in their publication on the global burden of diseases (WHO, 2004 update). The Institute for Health Metrics and Evaluation (IHME) in Seattle included estimates from the application of VAs for their recently published Burden of Disease Estimates 2010 which received global attention. These publications have global reach and significance and they are used by national governments and international agencies in informing their global health policies and planning. Another example demonstrating the use of the tool at national level is in Tanzania, where the Tanzanian Essential Health Interventions Project used the INDEPTH VA tool to generate district-level disease profiles which enabled district health officers to allocate

appropriate budgets based on the districts' disease burden.

Several international research institutions are now developing methods for the analysis of VAs. There have been meetings organized by WHO to discuss the application of methods such as FOREST (Institute of Health Metrics and Evaluation (a computer-aided technique for deducing cause of death), InterVA-4 (Umea). In December 2013, a new Working Group on VA was established by WHO; the INDEPTH Executive Director is a member of this Working Group. In 2010 and 2013 the Institute for Health Metrics and Evaluation organized a global scientific symposium on the application of the VA tool to give opportunity to researchers globally to share their experiences in the application of the VA tool and the analysis of the data generated. In 2012 INDEPTH was invited to be a member of the core group of institutions that regularly discuss issues related to the strengthening of civil registration and vital statistics (CRVS) systems in African countries. This group is led by the United Nations Economic Commission for Africa. The use of the shorter form of the VA is always a key item for discussion.

In terms of ongoing work, the Network and its collaborators are continually seeking to improve the tool and to take advantage of innovations in technology (e.g. computer-assisted interviewing and software for coding causes of death). INDEPTH's major advantage over other VA tool developers are the multiple sites which enable the Network to validate and generate cause of death data and mortality patterns in a range of settings.

4. Sources to corroborate the impact

- See "World Health Organization, Global Burden of Diseases, 2004 update. Geneva" as evidence of user of INDEPTH cause of death data.
- Institute for Health Metrics and Evaluation. Global Burden of Disease Estimates 2010 published extensively in The Lancet, The Journal of the American Medical Association. The publication was promoted by Bill Gates and IHME was invited to the White House in Washington to present this work which is based on VA application.
- Tanzania Essential Health Interventions Project: <http://www.idrc.ca/EN/Documents/Burden-of-disease.pdf>

5. Collaborators and their role

Other networks such as WHO and Population Health Metric Research Consortium were involved in the development and validation of the VA questionnaires. As indicated above, some of the collaborators made financial and technical contributions.

6. Funding

The funding for this research was contributed by many agencies and organizations including: WHO and funders who provide INDEPTH with core support.

Impact Case Study 2

NAME OF Coordinating HDSS CENTER:	INDEPTH Network Secretariat
TITLE OF IMPACT CASE STUDY:	Integrating data from INDEPTH Network’s Health and Demographic Surveillance System Centers and multiple household surveys to Monitoring vital events in Kenya.
CONTACT DETAILS:	Osman.Sankoh@indepth-network.org 38 & 40 Mensah Wood Street, East Legon P.O. Box KD213 Kanda Accra, Ghana
1. Summary of the impact	
<p>The INDEPTH Network has enabled its member Health and Demographic Surveillance System (HDSS) centers in Kenya to work closely with four key ministries of the government to improve their understanding of mortality trends and patterns in the country and to explore the use of the INDEPTH demographic surveillance system as a tool for improving coverage of civil registration of vital events in rural settings. The Secretariat organized a workshop in 2012 in Bellagio, bringing together leaders of four HDSS centers based in Kenya (Kisumu, Kilifi, Mbita, Nairobi) and representatives from the government of Kenya, led by the Director General of the Kenyan National Bureau of Statistics. A memorandum of understanding was reached and under this collaboration, a pilot study has commenced to institute vital registration systems based on existing surveillance structures in Kilifi and Kisumu HDSS as well as other interested HDSS. While it is too early to report population-level impacts, this collaboration has demonstrated that the HDSS is a viable platform for the Kenyan government to consider seriously as support for civil registration of vital events.</p>	
2. The role of the INDEPTH Network in enabling the impact	
<p>Kenya has five HDSS centers that are members of the INDEPTH Network. They include predominantly rural (Kilifi, Kisumu, Kombewa and Mbita) and an urban center (Nairobi). The Network supports these HDSS through training to improve the quality of the demographic surveillance data and capacity strengthening in data management, analysis, and funded places for master’s degrees. The data from the HDSS are used primarily for research and there is potential for their integration with census and household surveys to create powerful decision tools at the national level. For example, adult mortality patterns in the rural and urban HDSS complement each other, demonstrating the impact of urban-to-rural and rural-to-urban migration on mortality. The country’s wealth of census, household surveys, and administrative data is under-utilized, and there is even greater potential to inform national and sub-national policies when data from HDSS centers are integrated with these surveys. In addition, the demographic surveillance platform used by HDSS centers can be used to improve coverage of civil registration of vital events. These are the issues that led the INDEPTH Secretariat to use its convening powers to bring together key stakeholders in Kenya and representatives from four of its HDSS centers. The meeting took place in February 2013, in Bellagio, Italy and included representatives from four Kenyan HDSSs (Kilifi, Kisumu, Mbita and Nairobi) and key ministries (Ministry of Public Health and Sanitation; Ministry of Planning and National Development, Vision 2030; Ministry of Migration and Vital registration; Ministry of Medical Services) in a landmark event. The Director General of the Kenya National Bureau of Statistics led the government delegation. The meeting discussed the potential for using the demographic surveillance system data, the census, and survey data to develop methodology for identifying trends and patterns of mortality in the country and to develop methodology for improving vital registration especially in rural areas. A memorandum of understanding was reached and a technical working group was formed to spearhead joint actions including a proposal to INDEPTH for US\$10,000 to pilot the integration of census and HDSS data for the analysis of mortality patterns in Kenya. Another action was to explore the methodology for extending the tools used in demographic surveillance to improve civil registration of vital events.</p>	

3. Details of the impact

Although it is too early to measure population level impact, the collaboration has stimulated discussion between researchers and practitioners and is beginning to lead to changes in the way that vital events are recorded. The collaboration has also increased the profile of the Kenyan HDSS and the INDEPTH Network as a whole in the eyes of the Kenyan government.

The ultimate beneficiaries of this initiative are the people of Kenya, and the intermediate beneficiaries are the Kenya National Bureau of Statistics, the key ministries involved, (Ministry of Public Health and Sanitation; Ministry of Planning and National Development, Vision 2030; Ministry of Migration and Vital registration; Ministry of Medical Services), and the HDSS centers.

4. Sources to corroborate the impact**Names of persons**

- Dr Evasius Bauni, Kilifi HDSS, KEMRI/Wellcome Trust, Kenya. (EBauni@kemri-wellcome.org)
- Dr. Frank Odhiambo, Kisumu HDSS, KEMRI/CDC (fodhiambo@kemricdc.org)

5. Source of funding

INDEPTH provide a small grant of US \$10,000 (from its core support grants) to enable in-country collaboration. The network also provided support to the HDSS centers through capacity strengthening workshops. The four HDSS centers are funded by multiple sources including CDC, Wellcome Trust, and the William and Flora Hewlett Foundation.

Impact Case Study 3

NAME OF HDSS CENTER:	Agincourt HDSS MRC/Wits Rural Public Health and Health Transitions Research Unit
TITLE OF IMPACT CASE STUDY:	Influencing Policies to Prevent Hypertension and Strokes in South Africa
CONTACT DETAILS:	Rhian Twine. Email: Rhian.Twine@wits.ac.za Nicolette Pingo. Email: Nicolette.Pingo@wits.ac.za Stephen Tollman. Email: Stephen.Tollman@wits.ac.za , +27 11 717 2343
1. Summary of the impact	
<p>With over a decade of research into blood pressure as an important facet of the rapid epidemiological transition in rural South and Southern Africa, the MRC/Wits-Agincourt Unit has influenced policies and practice at local, district, provincial and national levels. Sustained relationships with multiple stakeholders resulted in responses with potential for major public health impact. Research since 2002/3 demonstrated that about 43% of the Agincourt population had hypertension, that reducing the sodium content of bread would reduce population-wide systolic blood pressure nationally, and prevent about 2000 fatal and 2300 non-fatal strokes annually. In addition to salt, smoking and obesity were found to be critical risk factors for strokes. The research led to: development of national stroke prevention initiatives; changes in national policy regarding salt content in foods; and research into health system interventions for integrated chronic disease management in partnership with the Ministry of Health.</p>	
2. The underpinning research	
<p>A key aspect of the rapid epidemiological transitions being faced in rural South and Southern Africa is a simultaneous increase in non-communicable and communicable diseases, most notably HIV/AIDS and stroke. The HDSS has provided integral data highlighting this transition.</p> <p>SASPI Work on Hypertension and stroke (2002/3-2006): Having noted increased mortality due to non-communicable diseases, in particular strokes, through its annual census round and verbal autopsies, the MRC/Wits-Agincourt Unit established the South African Stroke Prevention Initiative (SASPI) with colleagues from the London School of Hygiene and Tropical Medicine. The SASPI team conducted several studies on hypertension and its consequences, in particular stroke. These studies explored various facets of blood pressure in the MRC/Wits-Agincourt HDSS:</p> <ul style="list-style-type: none"> (i) The research highlighted the prevalence of hypertension, with some 43% of the population having some degree of hypertension [1,2]. (ii) A nested study on 402 participants who had had a stroke, highlighted critical behavioral risks for hypertension including obesity, high salt content in the diet and smoking [1]. (iii) Further investigation into health system management of hypertension resulted in an audit of blood-pressure-devices [3]. <p>National Focus on Salt content in manufactured food (2011-2013): These studies into hypertension within the MRC/Wits-Agincourt sub-district led to a national level focus on hypertension, again highlighting its critical linkage to stroke. The PRiority Cost Effective LEssons for System Strengthening (PRICELESS) is a critical health economic unit with the MRC/Wits-Agincourt Unit. In 2011, PRICELESS embarked on exploring the national burden of stroke through excess salt consumption in processed foods [8,9,10]. The study estimated the number of lives that could be saved by reducing salt in manufactured food. The researchers showed that reducing the sodium content of bread would reduce population-wide systolic blood pressure, and prevent about 2000 fatal and 2300 non-fatal strokes annually. The work highlighted the savings from reduced numbers of hospital admissions of patients with non-fatal stroke alone could save ZAR300 million per year and prevent 3000 deaths from ischemic and hypertensive</p>	

heart disease.

Integrated Chronic Care (2012/13-2015):

The work on hypertension, in partnership with the Wits Centre for Health Policy and the University of Warwick, UK, was granted an award in 2012 by the UK MRC for critical work on ‘Treating hypertension in rural South Africa: Comparative effectiveness of two different patient outreach models’ in the MRC/Wits-Agincourt site. This project named *Nkateko*, takes a health systems approach to treating hypertension in rural South Africa. As a national pilot site for integrated chronic care, it is anticipated that the research will have an effect on the implementation of hypertension treatment across South Africa.

3. Details of the impact

The extensive research into hypertension in the MRC/Wits-Agincourt Unit has yielded positive impacts at local, district, provincial and national level. The timeline in Section 7 summarizes the research and major impacts on hypertension between 2002 and 2014

2003-2006 SASPI Study: Local Impacts

An integral part of the multi-disciplinary work on hypertension completed by the SASPI team was to disseminate the findings to the local community to highlight the risk behaviors for hypertension. This was achieved through drama in collaboration with a theatrical group [5]. The process allowed data validation, and elicited ideas for future interventions. Fact sheets on preventing hypertension and its effects and symptoms of stroke were shared with participants in the applied drama processes across the study site.

District, Provincial Level

In 2003, the SASPI team presented their results to the National and Provincial Departments of Health in Pretoria. The Deputy Director of Health Promotion in the Mpumalanga Department of Health took the results of the study, and used them to develop a project titled ‘Strengthening Capacity for Health Promotion in NCD Prevention in the Province of Mpumalanga’. This project, which was funded by WHO and the Flemish Government, aimed to reduce the burden of excess mortality and disability with regard to Cerebrovascular accident (strokes) and Cardiovascular disease by strengthening capacity for health promotion in three communities in Mpumalanga. The project was the first of its kind in South Africa, being a collaboration between the province, the National Department of Health, WHO and the Flemish funders.

2011-2013 Salt Content in Manufactured food: National Level

The research by Agincourt/PRICELESS on salt content resulted in amendments to regulations in the Food, Cosmetics and Disinfectants Act to reduce salt content in manufactured food, announced by the Minister of Health in 2013, to be implemented in 2016. Several key processes in engaging with government to ensure success were followed [9]:

- (i) ensuring that relevant stakeholders were involved from the outset, including a participatory process to design key research questions;
- (ii) keeping communication channels open throughout the process and informing stakeholders of results as they emerged,
- (iii) researcher involvement in consultative processes with both industry and the media ensuring that these interest groups were correctly informed.

These regulation amendments will impact all South Africans who consume manufactured food products, most notably bread. It will have further impacts on sub-Saharan Africa since multiple South African manufactured food products are available across the continent.

2012/3-2015 Integrated Chronic Care: Local

The Agincourt HDSS area has been established as a National Pilot site for integrated chronic care.

It is in this context that two patient models will be tested in relation to hypertension treatment. The intervention arm of the study will build on the integrated chronic care model with the introduction of lay health worker. The study based in clinics is reliant on both local and provincial health department partnerships. The intervention adds additional capacity to local clinics through the lay health worker working directly with a nurse in the clinic and providing support to the patients.

4. Sources to corroborate the impact

SASPI Study: District/Provincial Level

Mrs Heila Jooste- Health Promotion, Mpumalanga Department of Health and Social Services, Nelspruit. Tel: +27 82 822 6041 Email: heilaj@social.mpu.gov.za

Salt Content Regulation: National

The PRICELESS Steering Committee has several influential government and South African Medical Research Council representatives guiding its core work. These relationships have been integral in building a sustained relationship with the Minister of Health, Dr Aaron Motsoaledi specifically through the Director General Dr Precious Matsoso and high level Department of Health representatives, including Dr Yogan Pillay, Dr Melvyn Freeman and Thulani Masilela who is now in the Presidency. The primary contact person at the Department of Health with regard to the salt content work is:

Melvyn Freeman, Cluster Manager Non-communicable diseases of the National Department of Health

Tel: +27 12 395 8020 Email: FreemM@health.gov.za/mfreeman@telkomsa.net

PA: Tebogo Lekalakala Tel: +27 012 395 9055 Email: lekalt@health.gov.za

The salt work produced extensive media debate and discussion in South Africa, a full listing of media coverage can be found here: <http://www.priceless.ac.za/News/Pages/Media.aspx>

Integrated Chronic Care: Local

Sarah Gumede, Department of Health, Mpumalanga Province

Tel: +27 137663145 Email: sarahg@social.mpu.gov.za or sarah.gumede@yahoo.com

5. Role of the Secretariat and other Networks

INDEPTH Network and Other HDSS: The INDEPTH Network and other HDSS were not directly involved in the hypertension study described above. However, the MRC/Wits-Agincourt Unit led the INDEPTH-WHO SAGE study, which included critical questions on hypertension and stroke for populations aged 50+ in 4 African and 4 Asian INDEPTH sites. Furthering this work, the MRC/Wits-Agincourt Unit together with Ifakara and Navrongo INDEPTH Centers will be conducting an extensive study in Adult Health and Ageing in Africa: Longitudinal Studies of INDEPTH communities (HAALSI). This study will build on the work described above with a questionnaire examining risk factors for hypertension and blood pressure.

Collaborators: University of the Witwatersrand, South Africa; University of Warwick, UK, Mpumalanga Provincial Department of Health, and the National Department of Health

6. Funding

Research: The MRC/Wits Agincourt Unit's work has been supported by various organisations throughout its extensive research into hypertension. These have provided support in various ways for both research and impact acceleration. The most relevant financial contributions for the work described above are: the Wellcome Trust and the Medical Research Council, UK; the University of the Witwatersrand and MRC South Africa; National Institute on Aging, NIH, USA; and IDRC, Canada.

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Section 7: Timeline of Impacts

Hypertension Studies and Impacts in Agincourt HDSS 2002-2014

Research

2002: Hypertension screening question embedded in Agincourt HDSS census highlighted high prevalence of hypertension and stroke.

2002/3-2006: Formation of South African Stroke Prevention Initiative (SASPI) & multi-disciplinary research into hypertension and stroke.

2010: HIV NCD Study Chronic Disease Risk Factor Surveillance conducted in Agincourt.

2011-2013: PRICELESS, Agincourt sub-unit conducts research on the impacts of reducing salt content in manufactured food in decreasing hypertension and stroke.

2012/3-2015: Nkateko project on treating hypertension in rural South Africa.

Impacts

Local: Applied drama process used to disseminate research findings and provide residents with facts about hypertension and stroke.

District/Provincial: Presentation of SASPI results to provincial and National government, leads to WHO supported programme on NCD prevention implemented in 3 areas of the Mpumalanga province.

National: Regulations limiting salt content in manufactured food (in particular bread) is declared in 2013, to be implemented in 2016.

National: Major media coverage, debates and discussions on salt content regulations.

Local: Several Clinics in Agincourt set up as National Pilot sites for integrated chronic care.

All studies conducted in Agincourt include community entry and feedback from the INC (Learning Information Dissemination and Networking with Communities) office as well as where relevant patient referrals to clinics and hospitals.

Impact Case Study 4

NAME OF HDSS CENTER:	Dodowa Health Research Centre
TITLE OF IMPACT CASE STUDY:	Improving policies for home management of fevers in children under-five years in Ghana
CONTACT DETAILS:	margaret.gyapong@ghsmail.org ; blancaescribano2@gmail.com
7. Summary of the impact	
<p>Research conducted at the Dodowa Health Research Centre (DHRC) has influenced the Government of Ghana's health policy on the home management of fevers among under-five children. The research conducted between 2007 and 2009 in Dangme West district showed that using antimalarial only for home management of fevers was just as effective in reducing under-five mortality as using antimalarial plus antibiotics. Furthermore, the results showed that the home-based management of fevers with antimalarial only was more cost-effective than antimalarial plus antibiotics. These findings provided evidence for continuation of the existing national strategy in home management of fevers among children using antimalarial only for fevers and to prescribe antibiotics only when there are respiratory signs of pneumonia.</p>	
8. The underpinning research	
<p>According to the nationally representative Ghana Demographic and Health Surveys (DHS) conducted between the 1998 and 2003, the under-five mortality rate in Ghana marginally increased between the period from 108 to 111 deaths per 1000 live births. The main causes of under-five death in Ghana are thought to be malaria, diarrhoea, and pneumonia. The 2008 Ghana DHS estimated that about 20% of under-five children in the country had fever in the two weeks before the survey, 20% had diarrhoea, and about 6% had acute respiratory infections. During that period, the home management of fevers among under-five children was presumptive treatment with antimalarial drugs but excluded pneumonia.</p> <p>The research carried out by DHRC between 2007 and 2009 aimed to evaluate the impact on under-five mortality of adding an antibiotic (amoxicillin) to an antimalarial (artesunate amodiaquine) for treating fevers among children within the Home Based Care (HBC) strategy. Another component of the study sought to assess the cost effectiveness of the two approaches (antimalarial or antimalarial plus antibiotic). The research was collaborative between DHRC, Ghana Health Services, and international partners (see Section 5). The research design was a stepped-wedge cluster-randomized, open trial, with children 2-59 months of age with fever treated with either antimalarial only or antimalarial and antibiotic within the HBC. Historical controls were used. During the course of the trial, Rapid Diagnostic Test was introduced, giving an opportunity to distinguish between malaria and pneumonia.</p> <p>The findings showed that under-five mortality was reduced by 30% in those using antimalarial, by 44% in those using antimalarial and antibiotic, compared with the standard care. However, there was no statistically significant difference in under-five mortality between the groups who received antimalarial alone and those who were given antimalarial plus an antibiotic.</p> <p>The cost-effectiveness study of the two strategies of home management of fevers among under-five children in Ghana showed that both approaches were cost-effective, each averting one DALY at less than the standard US\$150 threshold recommended by the World Health Organization. However, antimalarial only was more cost-effective.</p>	
Reference	

Chinbuah M, Kager P, M. A. Impact of Community Management of Fever (Using Antimalarials With or Without Antibiotics) on Childhood Mortality: A Cluster-Randomized Controlled Trial in Ghana. *Am J Trop Med Hyg.* 2012; 87(Supplement 5):11-30.

Nonvignon J, Chinbuah M, Gyapong M, al. e. Is home management of fevers a cost-effective way of reducing under-five mortality in Africa? The case of a rural Ghanaian District. *Tropical Medicine and International Health* 2012; 17(6).

9. Details of the impact

The research findings were disseminated to several stakeholders using a range of mechanisms including: a) community meetings during the course of the study; b) at national level; c) the World Health Organization in 2009; and d) at the Global Health Forum in Geneva in 2008: "Development of a Strategy for Home and Community Management of Malaria and Pneumonia in Children Under Five in Southern Ghana".

The main impact of the research was to add further evidence of the efficacy of the existing strategy for home based care of fevers in Ghana that was already being implemented. The nature of the impact was in a supportive way, bringing more evidence of the efficacy of the current Home Based Care (HBC) strategy for fevers in Ghana which recommends treatment with antimalarial and amoxicillin only when there are respiratory signs of pneumonia. According to officials in the Ghana Health Services, the research promoted greater researcher-policymaker interaction and increased the researchers' political capital. Researchers with greater political capital are credible and valued by policy makers, and they have more leverage in influencing policies. The researchers also gained by being part of policy networks including INDEPTH, the Special Program for Research and Training in Tropical Diseases (TDR/WHO) and the ICCM (integrated community case management of childhood illness) task force.

The research conducted by DHRC, by influencing the HBC strategy, has benefitted millions of children in Ghana. By providing antibiotics only when there are signs of pneumonia, the Ghana government is saving millions of dollars annually. The research also made an impact on the community by stimulating debate on how to better manage fevers among under-five children.

10. Sources to corroborate the impact

- Ministry of Health, Ghana Health Service, Global Fund, WHO, USAID, CDC, Home Management of Malaria, ARI, and Diarrhoea in Ghana. Implementation Guidelines, 2010.
- Ministry of Health. Anti-malaria drug policy for Ghana. 2009.
- Ministry of Health. Guidelines for case management of malaria in Ghana. 2009.

Contacts:

Dr Abraham Hodgson, Director Research and Development, Ghana Health Services, Accra.

11. Role of the Secretariat and other Networks

While the INDEPTH Network did not directly fund this specific research project, Dodowa Health Research Centre is a member of the INDEPTH Network and therefore receives support through training of staff linked to the demographic surveillance system. The Network also provides training for scientists in data management and analysis.

Other collaborators: World Health Organization, University of Makerere, Ghana Health Services (Malaria and Child Health programs), University of Amsterdam, and University of Maastricht.

12. Funding

The Center was awarded US\$856,000 in a competitive call by the World Health Organization.

Impact Case Study 5

NAME OF HDSS CENTER:	Manhiça Health Research Centre
TITLE OF IMPACT CASE STUDY:	Influence on pneumonia vaccine policies in Mozambique
CONTACT DETAILS:	<p>Eusébio V. Macete, MD PhD Director Centro de Investigação em Saúde de Manhiça (CISM) Tel./Fax: (+ 258) 21 81 00 02/181 CP 1929 Maputo - Moçambique Página Web: www.manhica.org E-mail: eusebio.macete@manhica.net</p>
13. Summary of the impact	
<p>The Manhiça Health Research Centre (CISM) has played a major role in generating knowledge for fighting against prevalent diseases in Mozambique and the region. Studies conducted by the CISM have guided the health authorities and decision-making bodies to define or adjust health policies. Specifically, research conducted by CISM in 2009 demonstrated the high burden of pneumonia among children in Mozambique, showing high incidence of 416/100,000 child-year at risk (reaching 779/100,000 in children under 3 months of age), with a case fatality rate of 10%. These findings prompted the government to request assistance from GAVI in 2009 to introduce the Haemophilus influenzae type b (Hib).</p> <p>Using the HDSS platform, the center monitored pneumonia cases among children and showed that among children under 1 and 5 years of age, significant reductions occurred in the rates of invasive Hib disease (91% and 85%, respectively), and for very severe pneumonia, the reductions were 29% and 34%, respectively. Similarly, research by CISM which demonstrated the benefit of the Pneumococcal Conjugate vaccine, prompted its roll-out in the country in 2013.</p>	
14. The underpinning research	
<p>Pneumonia is the leading cause of morbidity and mortality among children under 5 years of age worldwide, with roughly 13% of deaths due to this cause. The majority of these deaths occur in low income countries, and other causes include diarrhoea, prematurity, and malaria. While these global statistics are important, it is often desirable to generate local epidemiological data so that specific prevention programs and interventions appropriate for distinct populations are designed. In addition, local statistics of the burden of diseases enables decision makers to make appropriate health policies and allocation of resources.</p> <p>The Manhiça Health Research Centre, established in 1996 in a rural area of southern Mozambique, currently follows around 92,000 individuals living in approximately 20,000 enumerated and geo-positioned households. Its main strength is the ability to link demographic data and clinical data to promote and conduct biomedical research in priority health areas. CISM initially started by conducting socio-demographic observational studies to describe patterns and trends of fertility, migration, morbidity, and mortality in the area. CISM has now widened its scope to include more in-depth molecular, immunological, and entomological studies, as well as clinical trials and the evaluation of interventions. Since 1998, the Centre has conducted epidemiological surveillance on the etiology of pneumonias, bacteraemia and meningitis in children in the Manhiça District Hospital (MDH), focusing on characterizing the burden of disease, antibiotic resistance, improvement of diagnosis, and evaluation of control strategies. CISM also operates a round-the-clock, hospital-based morbidity surveillance system for children under 15 years of age attending the Manhiça District Hospital and three other peripheral health facilities in the study area.</p> <p>The work leading to the introduction of the pneumonia vaccines was disseminated in 2006, when the Center reported data on the epidemiology of pneumococcal invasive diseases in children under 5</p>	

years of age, that showed an incidence of 416/100,000 child-year at risk (reaching 779/100,000 in children under 3 months of age), with a case fatality rate of 10% (rising to 56% in children with meningitis caused by this micro-organism). The studies carried out at the Center also demonstrated that a considerable proportion of pneumonia cases and deaths are caused by bacterial agents, among which *Streptococcus pneumoniae* and *Haemophilus influenzae* type b are the most prevalent.

Between 2011-2013, the Manhica HDSS assessed the impact of the introduction of Hib vaccine on invasive Hib disease and pneumonia, measuring the burden of pneumococcal disease and preparing an impact evaluation of pneumococcal vaccines. The effectiveness study, conducted within the Morbidity Surveillance System at the CISM, compared the incidence of Hib invasive disease, before and after the vaccine introduction, and also by concomitantly carrying out a specific case-control study to assess risk factors for Hib invasive disease. The findings demonstrated significant reductions in invasive disease and pneumonia after the introduction of the Hib vaccine. Among children under 1 and 5 years of age, significant reductions occurred in the rates of invasive Hib disease (91% and 85%, respectively) and very severe pneumonia (29% and 34%, respectively). The incidence of confirmed pneumonia significantly reduced by 33% in children under two years of age.

Invasive pneumococcal disease (IPD) was defined as an important cause of illness and death among under five children in Mozambique. Research from CISM monitored the incidence of IPD and the effectiveness of Pneumococcal conjugate vaccine (PCV) over a 10-year period (January 2001 to December 2010). The results demonstrated that most IPD episodes and many deaths among children under five in rural Mozambique could be prevented if PCV was introduced.

15. Details of the impact

The main impact of this research was the introduction in the country of the *Haemophilus influenzae type b (Hib) vaccine (Hib vaccine)* in Mozambique in 2009 and the introduction in April 2013 of the *Pneumococcal conjugate vaccine (PCV-10)*, as part of Mozambican routine immunization program. The main beneficiaries from the research conducted at CISM are the general population and public health authorities including the Ministry of Health's National Institute of Health, National Control Programs, and National Directorate of Public Health. By demonstrating the burden of diseases, the research has enabled the Government to act (for example in requesting vaccines from GAVI) and to introduce policies and programs designed to reduce the burden of diseases among the population.

CISM's research makes a valuable contribution to improving the health of the population in Mozambique. In 2008, the President of Mozambique visited CISM as a demonstration of the value placed by the country on the work of the Center and in 2014, he awarded the Center with the prestigious *Medalha Bagamoyo*, which was in recognition of the Center's essential research and contribution to the development of the country. Other dignitaries that have visited CISM in the past few years include the First Lady of Mozambique (2013), the Queen of Spain (2013), and several ambassadors. Although there have been no local economic valuations of the research on the vaccines, the benefits in terms of lives saved, quality of life, and reduction in treatment and healthcare costs are obvious.

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Sacarlal J, Nhacolo AQ, Sigaúque B, Nhalungo DA, Abacassamo F, Sacoor CN, Aide P, Machevo S, Nhampossa T, Macete EV, Bassat Q, David C, Bardaji A, Letang E, Saúte F, Aponte JJ, Thompson R and Alonso PL. A 10 year study of the cause of death in children under 15 years in Manhiça, Mozambique. *BMC Public Health* 2009, 9:67 doi:10.1186/1471-2458-9-67

Sigauque B., D. Vubil, A. Sozinho, et al. "Haemophilus influenzae Type b Disease among Children in Rural Mozambique: Impact of Vaccine Introduction." *J Pediatr.* 163.1 Suppl (2013): S19–24

16. Sources to corroborate the impact

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17. Role of the Secretariat and other Networks

The CISM is a founding member of the INDEPTH Network, therefore the Manhiça HDSS data are shared within the INDEPTH Network for different types of multicenter analyses and within the different INDEPTH specific working groups in which Manhiça has been invited to participate. As part of the center's activities in the context of the INDEPTH Network, the Demography Department participated in the creation of the migration monograph published by the Network. The department also has a key role in the provision of support to new research centers in sub-Saharan Africa that wish to create a DSS. Specifically, the department is currently providing support to the Centro de Investigação e Treinamento em Saúde de Chokwé in Chokwé, Mozambique and to the Centro de Investigação em Saúde de Angola in Caxito, Angola.

18. Funding

The financing of CISM is based on two fundamental usual mechanisms for research centers. First, a stable public funding to ensure its operation. Secondly, the capture of competitive funds (public and private) for specific projects led by researchers. The Manhiça HDSS is part of the CISM core activities, funded since 1996 by the Spanish Agency for International Development and Cooperation.

Impact Case Study 6

NAME OF HDSS CENTER:	Nairobi Urban Health and Demographic Surveillance System (NUHDSS)
TITLE OF IMPACT CASE STUDY:	Cardio Vascular Disease (CVD) risk factor assessment study
CONTACT DETAILS:	Dr Catherine Kyobutungi APHRC Campus, Manga Close, Off Kirawa Road P. O. Box 10787, 00100-GPO, Nairobi – Kenya ckyobutungi@aphrc.org
19. Summary of the impact	
<p>The Cardio Vascular Disease (CVD) study conducted by the African Population and Health Research Center (APHRC) led to the decision by the City Council of Nairobi (CCN) to prioritize CVD management in its primary health care facilities. Findings showed high prevalence of overweight and obesity particularly among females (43%) in the two slums of the Nairobi Urban HDSS, and hypertension and diabetes age-standardized prevalence of 18.4% and 5.4%, respectively, among adults aged 18+ years (37% and 11% among older adults aged 50+). As a result, the CCN established 10 clinics through the rapid results initiative. To date, there are at least six active CVD clinics in CCN health facilities. Two patient support groups were registered as Community Based Organizations in the two NUHDSS slums, with members contributing monthly to a drug revolving fund, entitling them to treatment and a month's supply of drugs. The clinics are each handling about 200 patients every month and all newly diagnosed patients are enrolled in the support groups.</p>	
20. The underpinning research	
<p>The main objective of the CVD risk factor assessment study was to assess the linkages between socioeconomic and sociocultural factors, perceived personal risk for cardiovascular disease, and health behavior in the Korogocho and Viwandani slums of Nairobi. The survey was conducted from May 2008 through April 2009 as part of the Nairobi Urban and Health Demographic Surveillance System (NUHDSS). A total of 5,190 residents of the 2 slums were randomly selected and stratified by sex and age using a sampling frame that included all adults aged 18 years or older in the NUHDSS. Data on their tobacco use, alcohol consumption, diet and physical activity, and biomarkers of CVD physiological risk factors among others were collected.</p> <p>Findings showed high prevalence of overweight and obesity particularly among females (43%) in the two slums, and hypertension and diabetes age-standardized prevalence of 18.4% and 5.4%, respectively, among adults aged 18+ (37% and 11% among older adults aged 50+) [1, 2]. Another key finding was low levels of awareness (previous diagnosis) among patients with hypertension and diabetes (20%) that led to low treatment levels [3]. Low control levels of key CVD risk factors portend a high likelihood of medium to long-term CVD end-points in this population; urgent measures are required to increase awareness and treatment levels, and to reduce other risk factors.</p> <p>During the survey, it was realized that no health services were available to manage study participants found to be with CVD risk factors such as high blood pressure and diabetes. The project therefore established outreach clinics to manage the participants that needed care. The clinics were established in conjunction with the City Council of Nairobi (CCN) and a local NGO – Kenya Diabetes Management and Information Center (DMI). Based on experiences from these clinics, the project team together with the CCN and DMI applied for a grant from the World Diabetes Foundation for support in running the clinics beyond the life of the project.</p>	
References	
<ol style="list-style-type: none"> van de Vijver SJ, Oti SO, Agyemang C, Gomez GB, Kyobutungi C. Prevalence, awareness, treatment and control of hypertension among slum dwellers in Nairobi, Kenya. <i>Journal of hypertension</i>. 2013;31(5):1018-24. 	

2. Oti SO, van de Vijver SJM, Agyemang C, Kyobutungi C. The magnitude of diabetes and its association with obesity in the slums of Nairobi, Kenya: results from a cross-sectional survey. *Tropical Medicine & International Health*. 2013;18(12):1520-30.
3. Ettarh R, Van de Vijver S, Oti S, Kyobutungi C. Overweight, Obesity, and Perception of Body Image Among Slum Residents in Nairobi, Kenya, 2008-2009. *Preventing Chronic Disease*. 2014;11:E212.
4. APHRC. Cardiovascular diseases risk factors among the urban poor. APHRC Fact sheet No. 3. 2010.

21. Details of the impact

Apart from the scientific papers, the findings were also disseminated through a workshop whose participants included officials from the Ministry of Health – Division of non-Communicable Diseases, CCN, NGOs, Nairobi Provincial Health Office, etc. A factsheet on CVD risk factors among the urban poor was developed and widely shared (4).

The project team had regular interactions with the CCN officer in charge of CVD, the CCN Medical officer, the Provincial Health team and DMI staff. These interactions culminated in the joint application to the World Diabetes Foundation (WDF) which was successful. The WDF-funded work entailed expanding the capacity of primary health care facilities with the CCN to provide care for patients with high blood pressure and diabetes. The CCN identified the health facilities which were then given equipment for diagnosing and monitoring patients with the two CVD conditions and their staff trained in protocols for patient management. Through the WDF-funded project, we established five CVD clinics within the CCN health facilities. The established clinics provided evidence to the CCN health department on the burden of CVD conditions and the huge demand for services. As a result of these activities, the CCN decided to prioritize CVD management in its primary health care facilities and to establish 10 clinics through a performance mechanism known as the rapid results initiative. Some of the clinics supported under the WDF-funded project were incorporated in this initiative. To date, there are at least six active CVD clinics in CCN health facilities.

Another outcome from the two research projects was the establishment of two patient support groups, one in each of the two NUHDSS slums. The members of these groups were former patients in the outreach clinics. The two groups were then registered as community-based organizations (CBOs). A management structure was established in each and members started paying a monthly subscription fee dependent on their diagnosis. Payment of the fee entitled them to treatment and a months' supply of drugs. This system was set up as a sustainability mechanism once the WDF funding ended. With support from CCN, the clinics are being run in two of their health facilities. Some patients were trained as "expert patients" and they support the trained clinician during clinic days to manage the heavy workload. The WDF project provided funds for a drug revolving fund that is replenished with the monthly membership subscription. Drugs and other supplies are purchased in bulk from a government subsidized facility. The clinics are each handling about 200 patients every month and all newly diagnosed patients are referred to the support group for enrolment since this is the only mechanism through which they can access essential drugs and supplies.

22. Sources to corroborate the impact

- 1) Mr. Peter Ngatia (CCN rapid results initiative) - +254722372223; peterngatia@yahoo.com
- 2) Ms. Shillah Mwaniga (Outreach clinics in CCN) - +254714891698; smwaniga@yahoo.com
- 3) Mr. Robert Maregwa (Patient support group in Viwandani) - +2540721286686

23. Role of the Secretariat and other Networks

No direct role played by the secretariat, other than routine network support activities for the NUHDSS (e.g. workshops, trainings, working groups)

24. Funding

The Wellcome Trust and World Diabetes Foundation for both the research and impact acceleration

APPENDIX FOUR - List of People Consulted

INDEPTH Board of Trustees

Prof Marcel Tanner (Chair)
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