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Special Article

Advancing non-communicable diseases research in Ghana: key stakeholders' recommendations from a symposium

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SUMMARY

There has been a growing increase in the prevalence of non-communicable diseases (NCDs) globally with reports suggesting that the fastest increase in NCD deaths in the world will occur in sub-Saharan Africa (SSA) over the next 5 to 15 years. Despite the projected increase in NCD-related deaths, there is little coordinated research in many West African nations, including Ghana, to quantify and study this burden and to translate the research findings into policy and practice. To address these challenges, the Noguchi Memorial Institute for Medical Research and the Navrongo Health Research Centre, both in Ghana, with support from the Wits NCD Research Leadership Training Program organized a two-day symposium to discuss the advancement of NCD research in the West African sub-region. The aim was to propose the way forward for strengthening applied research that can inform the development of health policies and programs focused on NCDs. Participants were drawn from academia, research and health institutions, early career researchers and postdoctoral fellows. We present the key themes that emerged from the symposium and some strategies for advancing NCD research in West Africa. These include interdisciplinary collaboration between NCD researchers in the region, generation of accurate data on disease burden and strengthening stakeholder and public engagement on NCDs.

Keywords: non-communicable diseases, health research, collaboration, public engagement, network
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INTRODUCTION

The prevalence of non-communicable diseases (NCDs) is increasing globally and is currently the leading cause of death and disease burden worldwide. The World Health Organization (WHO) has predicted that by the year 2020 the fastest increase in NCD deaths in the world will occur in sub-Saharan Africa (SSA) and that by 2030, NCDs will become the leading cause of death in this region (accounting for 42% of all deaths).[1]

NCDs include cardiovascular diseases (stroke, hypertension), cancer, diabetes, kidney disease and mental health disorders. Until recently, these diseases were regarded as diseases of high-income countries or as affecting only the wealthy and the elderly in low- and middle-income countries (LMICs) and thus little attention was given to NCD research in LMICs, including Ghana.

This trend is changing as a larger cross section of the population in this region is affected and this can be attributed to rapid urbanization accompanied by significant changes in lifestyle, particularly dietary intake and levels of physical activity.[2] Also, growing funding and research initiatives such as the Human Heredity and Health in Africa (H3Africa) Consortium has drawn some attention to the need to accelerate NCDs research on the continent.[3] For example, Ghana is primary and co-host to several collaborative projects under the H3Africa Consortium including the AWI-Gen[4]

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Collaborative Centre which focuses on cardio-metabolic diseases, the Kidney Research Network[5] and the Stroke Investigative Research Network (SIREN).[6]

Despite the growing burden of NCDs in sub-Saharan Africa, there remains little NCD research and few large research cohorts are being developed. To help address these gaps, the Noguchi Memorial Institute for Medical Research and the Navrongo Health Research Centre in Ghana, both in Ghana, and with support from the University of the Witwatersrand (Wits) Non-Communicable Disease Research Leadership Training Program, a dynamic, cross-disciplinary program aimed at nurturing future leaders in non-communicable disease research on the African continent[7], organised a two-day symposium in Accra, Ghana on 14th and 15th March 2017. The aim was to provide a platform for NCD researchers and key stakeholders to deliberate on the key research gaps in NCD research, with special focus on longitudinal and genomic studies and to make recommendations on how to bridge the gap between research, policy and practice.

In all, 75 participants from Ghana, Nigeria, South Africa and the Netherlands, representing twenty-three (23) institutions (appendix 1) participated in the symposium. Participants were drawn from academia, health research institutions, policy makers, healthcare providers. Day one focused on presentations by seven facilitators on topics ranging from longitudinal cohort studies, genomic research and ethics. Day 2 was a smaller group of about 25 key people who had in-depth deliberations on the highlights of the presentations and to formulate key recommendations.

Here, we present the key themes that emerged from the symposium and some strategies for advancing NCD research in West Africa including strengthening coordination between NCD researchers, developing effective research tools that can provide accurate data on the burden of diseases and strengthening stakeholder and public engagement on NCDs.

CURRENT CHALLENGES

Challenges with estimating the burden of NCDs in Ghana

One of the key challenges that were highlighted at the symposium was lack of prevalence data on most NCDs in Ghana. A few studies have suggested that NCDs are increasing at an alarming rate and will become one of the leading causes of morbidity and mortality in these countries. The current burden of NCDs in many countries in sub-Saharan Africa such as Ghana is difficult to estimate due to the paucity of data and statistics in morbidity and mortality of NCDs. In 2011, a systematic review by Dalal et al.[8] found that the prevalence of NCDs and risk factors varied considerably between countries globally. The prevalence of stroke ranged from 0.07 to 0.3%, diabetes mellitus from 0 to 16%, hypertension from 6 to 48%, obesity from 0.4 to 43% and current smoking from 0.4 to 71%. The authors concluded that the prevalence of NCDs and their risk factors is high in some SSA settings and recommended that epidemiologic studies with 'a variety of designs (cross-sectional, longitudinal and interventional) capable of in-depth analyses of risk factors could provide a better understanding of NCDs in SSA, and inform health-care policy to mitigate the oncoming NCD epidemic'.

Participants at the NCD symposium suggested that most of the existing NCDs data are from small research projects at the institutional level and because these data are not being fed into any national registry it is often difficult to estimate the burden of NCDs in the country. Concerns were also raised about the quality of data at the institutional level coupled with the lack of appropriate data collection tools with standardized variables and indicators for monitoring NCDs. Some were of the view that the District Health Information Management System (DHIMS) needs to be strengthened to provide accurate data that can feed into a national registry on NCDs.

NCD policy and implementation

Another issue that was raised by participants was the need to strengthen the implementation of the NCDs policies at the national, regional and district levels. Participants' concerns were similar to Bosu's comprehensive review of Ghana's policy and programmatic response to NCDs which suggested that despite the existence of a national policy and control strategy for NCDs in Ghana and the many initiatives that have aimed at the prevention and control of NCDs, there have been major challenges with implementing these strategies. These include inefficient programme management, low funding, little political interest, low community awareness, high cost of drugs and absence of structured screening programmes. The author has suggested that what is needed to improve the current situation will include improving political will; government's funding of a national cancer screening programme; basic and operational research; and using funds from well-resourced health programmes for overall health system strengthening.[9]

Lack of coordination of NCD research

The lack of coordination of the various NCD research activities that are being undertaken across the country was also raised as a big challenge.

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Participants noted that various researchers and institutions are conducting NCDs research, but these are not well coordinated. As well, collaborations between academia and health research institutions are often lacking. There were therefore calls for some form of harmonization of studies together with the strengthening of data management to address the burden of NCDs in the country. There were suggestions that the NCD programme of the Disease Control Unit of the Ghana Health Service could play this pivotal role with support from the Ministry of Health, working together with various stakeholders.

Limited funding for NCD research and advocacy

Participants at the symposium emphasized that most of the financial resources for NCD research in the Ghana are from external donors, although some local Universities are currently investing considerable funding. This is also true for other countries within West Africa. Most participants felt this model of research funding affects the types of studies that are conducted especially because the research agenda is often driven by the funders. This limits the capacity to address context specific problems through a systematic approach. Studies are also likely to be skewed towards certain diseases that may not be of priority to the country. The government was urged to deliberately provide resources in the areas of greatest need through its programming for health research and specifically for NCD research.

Participants' recommendations on the way forward

Participants suggested the following as the way forward to address the gaps in NCD research in Ghana and to strengthen knowledge translation that will promote healthy lifestyles among Ghanaians and prevent NCDs and related complications and mortality.

Developing a national research framework on NCDs

Participants suggested that there was the need for a National Research Framework that translates research into policy and implementation. Although a National Research Agenda (2015-2019) was recently published by the Health Research and Development Division of the Ghana Health Service which has some focus on NCDs[10], it was obvious from the discussions that most participants were not aware of this document and its content. Objective 6 of the National Research Agenda outlines various strategies that could be implemented to address NCDs in Ghana; which include implementation of the NCD control strategy, review and scale-up of the regenerative health and nutrition programme (RHNP); implementation of international conventions and treaties a including framework convention on tobacco control (FCTC); development and implementation the National Health Policy for the Aged; and strengthening of rehabilitation services. The document did not however cover emerging research fields such as genetics and genomics which are increasingly gaining recognition as a part of the way forward in addressing the burden of NCDs in Africa. There were calls for greater attention to be given to gathering and reviewing evidence from available data sources to establish the true burden of NCDs across the country. A national platform for dealing with NCD research is required to coordinate efforts, ensure research meets needs and that research results are translated into policy and implemented at appropriate levels through sustainable programmes.

Apart from developing a national research framework, participants also highlighted the need to strengthen the NCD Unit of the Disease Control Division of the Ghana Health Service (GHS), to adopt a strong national surveillance system on NCDs and to use a multi-morbidity approach to tackle NCDs in order not to neglect any of the conditions.

Need for longitudinal cohort studies

NCDs develop over a lifetime and follow developmental pathways that will require time to allow for a full understanding. One key solution to gathering accurate data on the burden of NCDs is through the development of prospective cohort studies that follow participants longitudinally over decades. These types of studies can be used to study multiple complex diseases and risk factors simultaneously over an individual's lifetime. Such studies have proved crucial in understanding the etiology, course, and outcome of NCDs in other populations and have informed the design of prevention programs.[11,12] In addition, cohort studies provide an incomparable resource for the training of public health researchers. Because the payoff from cohort studies continues—and often grows—over time, they are a long-term investment in public health. The lack of cohort data on risk factors, with focus on genetic variations amongst the heterogeneous groups within the population was highlighted as another key challenge which needs to be addressed. Notable in Ghana is the Women's Health Study of Accra, which has enrolled 1,328 women to study the prevalence of communicable diseases and the context of NCDs.[13,14]

Participants highlighted the limited number of cohort studies in the country and called for more efforts to be made to build the necessary local capacity that can support longitudinal studies, especially including a genomics and epigenetics. These studies should also include studying the role of genetic variations and gene-environment interactions within the sub-regional populations as well as inter-ethnic groupings.

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Incorporating social and behavioral studies
Participants emphasized that there are several dimensions to addressing NCDs including change in attitudes, lifestyles and cultural practices. Thus, while efforts are being made to understand the gene-environment interactions that could be contributing to the increase in NCDs, it is important to also address the socio-cultural factors that are associated with the rise in these diseases. They suggested that research teams should be multidisciplinary and include social and behavioral studies that can address local beliefs about the causes of NCDs.

Strengthening public engagement on NCDs
The need for strong stakeholder communication and engagement on NCDs was raised as a critical issue that needs to be addressed to build trust with target communities and key stakeholders. Public engagement strategies could also be used to sensitize the Ghanaian public on the causes, prevention and treatment of NCDs. Most participants were concerned that some traditional healers and spiritualists are taking advantage of the lack of public sensitization on NCDs to market illegal and harmful concoctions to innocent patients which further worsens these diseases. Public engagement was also highlighted as important to support the successful conduct of NCD research and should be incorporated into the design and implementation of these studies.

Strengthening linkages between researchers and Research Ethics Committees
The session on ethics stressed the need for more collaboration between researchers and research ethics committees (RECs) to ensure that the requirements for ethics review are clear, that the system is streamlined to facilitate the ethical conduct of research and that social and behavioral studies are encouraged to not only address the burden of NCDs but also to inform the ethics review process.

The main outcome of the symposium was the decision to establish the West African Network on Applied Research on Non-Communicable Diseases (WANARON), which will aim at strengthening context specific and relevant research towards the prevention and control of NCDs in West Africa. The vision of the network is to support a nation that is driven and guided by sensible lifestyle and disease management choices based on accurate context-specific information on NCDs. Membership of the network is open to researchers, policy makers and practitioners who have an interest in NCD research.

The Network has identified the following key activities; provide training, mentorship and coaching opportunities for young and mid-career researchers, (with special focus on longitudinal and genomic studies), conduct collaborative research (with special focus on longitudinal and genomic studies), gather available evidence on NCD prevention and control, produce knowledge translation tools to facilitate advocacy for implementation of NCD research recommendations, support relevant agencies for translation of research into policy and practice and to collaborate with all relevant stakeholders in the sub-region engaged in NCD research and program implementation.

OUTCOME
The interactive symposium afforded participants the opportunity to network with other researchers working on NCDs from academic, health and research institutions and policy makers. There were calls for a formal platform that can encourage more collaborations and research on NCDs to inform practice and health policies. Some of the keyways in which NCDs research can be promoted in Ghana and the West African sub-region will include establishing a clear national research framework, strengthening public engagement on NCDs, and strengthening linkages between key NCD stakeholders. One of the outcomes of the symposium was a consensus to establish an NCD Network, West Africa Network on Applied Research in Non-Communicable Diseases (WANARON) that will bridge the gap between research, practice and policy.

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