Global health research: A view from the south on priority setting

Prof. Nelson K. Sewankambo
Makerere University, Faculty of Medicine
P. O. Box 7072, Kampala, Uganda
Tel: 256 41 530020, Fax: 256 41 532204

There is general recognition that health is a global public good and that health is a human right issue. As humans we have an ethical imperative to guarantee the right of all people to health despite background inequities in the world. To do this most effectively we need to progressively build a knowledge base through relevant health research. If this knowledge is disseminated widely and accessed freely around the world it should benefit all human kind as a global public good. Indeed health research and development has been defined by the WHO Commission on Macroeconomics and Health as a global public good (1). Despite enhanced communication and interaction in an era of globalization, the global system is failing those living in poverty. The benefits of scientific developments are not reaching the world’s poor people. Yet improving the health of the poor is a fundamental goal of development. There is need for a global strategy so as to effect change. A recent publication from the UK's Chief Medical Adviser states that a global health strategy needs to be underpinned by research, both in terms of understanding the problems that need addressing and the interventions required (2). It is extremely important to work together to tackle global health problems at national and international level. Indeed new opportunities have emerged for promoting international cooperation in research relevant to developing countries (3). Experience has taught us that working together across cultures, international boarders, between poor and rich countries can pose major moral and ethical challenges ranging from how to mobilize funding and other
resources (including human) and their allocation to issues of ownership and who is in charge.

Many new approaches, new organizations, new ways of thinking, new funds and new partnerships are taking place at a time when the developing world continues to experience a decline in the health of its population. At the turn of the last century the world has witnessed an extraordinary and unprecedented rise in the amount of financial resources directed towards some of the most pressing world health issues. These have come from donations and investments by both public and private sources like Foundations, Corporations, individuals, multilaterals and governments of nation states. Resources, however remain inadequate and much more money and sustained funding are still required to make a meaningful long term impact on global health. Whereas the reasons behind the motivation to participate in global health research may differ from one organization or country to another the fact remains that there are unprecedented opportunities for collaboration and uniting our efforts for a common purpose.

The efforts, however, are largely uncoordinated, at times competitive and sometimes there is evidence of outright unnecessary duplication. This may be coupled with lack of knowledge of effective interventions and strategies for optimal successful programme implementation.

Given the limited resources available and the extent of global health problems that are waiting to be addressed, we need to prioritise areas in order to obtain maximum benefit from investment. Priority setting has been emphasized to be as critical as conducting the research itself.
There are some very fundamental questions which need to be addressed as part and parcel of the priority setting process. Whose priorities or priorities for whom? How will developing countries meaningfully participate in the priority setting exercise? Other questions suggested by Keusch and Medline are: How should decisions be made? Who should participate, who should take the lead? In addition what methodology and tools to be used? What should the priorities be? (4)

**Underlying values**

The Commission on Health Research for Development recommended priority settings (5). More recently the Commission on Macroeconomics and Health has mandated research and development into diseases that are concentrated in poor countries (1). Must we undertake priority setting for research related to global health? It may be urged as the Commission has done that if for no other reason enlightened self interest is as compelling as humanitarianism as a justification for action.

Developing an acceptable and coherent global health research agenda with priorities will need to be anchored on an ethically acceptable path. Generally research is informed by value judgments which may be implicit or explicitly stated. Setting research priorities is even more value driven than the research itself. Also priority setting reflects ethical judgments as to the value of human life in different locations or situations and the best way of conserving or enhancing it. Is a life in
New York city the same value as one in the rural communities of northern Uganda?

Priority setting hinges on society’s recognition of the following principles:

a) The current situation of research funding is unacceptable. “Only 10% of health research funds from both public and private sources are devoted to 90% or more of the world’s health problems (measured in DALYs). Even the 10% of funds allocated to the 90% of world’s health problems are not used as effectively as possible, as health problems are often not prioritized using a defined methodology” (6)

b) Decision making should be as rational and as transparent as possible based on sound methods, scientific process and tools and in-built mechanisms to facilitate subsequent utilization of findings.

c) Health research is a critical element in health development. Health is a human right and health is global.

d) Health development should take place on the basis of social justice and equity. As emphasized by COHRED in ENHR.

e) The process of priority setting should emphasize inclusiveness involving all stakeholders including policy makers, research scientists, programme managers and civil society.

f) There should be a link between national priority setting that links or feeds into regional and
global priorities. Thus global priorities should be built upon a bottom up approach involving an upward synthesis of national priorities.

Implicit in the process of setting priorities is that choices will be made based on underlying values which are defined a priori. For a long time health maximization in terms of cost-effectiveness has been the stated value governing prioritization. With time other values have gained increasing recognition. These include for example severity of diseases which is incorporated in the burden of disease (BOD) assessment and equity in health outcomes. More values can be inferred from the principles proposed for prioritization of global health research by others like Labonte et al and by Pang (7,8) namely: fair treatment by ensuring sound ethical principles, avoiding exploitation and maximizing benefit for developing countries, participation of civil society, inequity in knowledge capacities (in north and south), the centrality of context focusing on global health determinants, increasing equity in health outcomes and concerns or questions identified by developing countries.

Which or whose values should be used to inform the global health research priority setting exercise?

There are two broad aspects to this question. Values might be at variance between people from the developing countries and those from developed ones because of contextual or social factors influences. On the other hand whereas using expert opinion facilitates methodology to be applied consistently across studies, the expert opinion may not reflect the opinion of society's
non expert members (9). The interests of community participants may also not reflect community interests (10).

Priority setting should not be an academic exercise but one that guides the investment portfolio of nations, organisations or institutions. The process of priority setting though largely political must be based on sound scientific methods and processes and be as objective and as transparent as possible showing accountability and based on (weighted) criteria that are agreed on by stakeholders. The latter’s participation enhances transparency of the process and accountability.

Equity has become a very important consideration in health service delivery and is increasingly being considered an essential criterion for research priority setting (11). Nuyens points out that only in exceptional circumstances has this criterion been used effectively (12). He rightly argues that there is need to establish how to operationalize equity as a criterion for priority setting, what information to collect and how to establish the political will to use this criterion.

The motivation and desire to enhance operationalisation of equity as a criterion is driven by a need to ensure social justice with particular interest in potential reduction of inequalities that are unfair and are systematically associated with underlying social or economic disadvantage to segments of society. Our concern for and our concept of unfairness are in themselves driven by various economic, social and political factors. Acceptance of equity as a criterion reflects a change in society's values and concern for elimination of unequal opportunities in health. This
concern has been embodied implicitly or explicitly in many health policies of countries and international organizations like WHO’s Health for All Strategy espoused in the Alma Ata declaration (13). Equity concerns have also been prominent in the Millennium Declaration and the subsequent Millennium Development Goals (14), (15).

Research priority setting frameworks need to be able to capture the issues of those with the greatest health needs and yet have the least resources to address them. As humankind we have a moral obligation to see that available resources are utilised efficiently and for the greatest benefit. When resources are constrained and thus demand exceeds the available resources priorities must be set among competing opportunities.

**Various approaches to research priority setting which have been used**

Research on methodologies to help set priorities in health research is a recent development and still in its infancy. The recommendations of the 1990 Commission have led to an increasing interest in this field and efforts to systematize the methods and processes (5). The field is steadily evolving with different approaches being advocated which pose challenging moral and ethical issues that unfold as more research priority setting is contemplated or undertaken. Different processes and methodologies have been used in the different efforts of priority setting. The common thread to all the approaches is trying to maximize health benefits to the greatest number of people whether internationally, regionally or nationally. The well known approaches so far include:
a) Using the Essential National Health Research Strategy (16)

b) Ad Hoc Committee on Health Research Approach (17)

c) Advisory Committee on Health Research Approach (18)

d) Global Forum for Health Research Combined Approach Matrix based on four domains (19)

e) The approach that combines burden of disease and “inherently global health issues” (7, 21)

Common to all the above is the burden of disease estimate which exposes the imbalance between research investment and disease burden i.e the 10/90 gap (16) and emphasizes vulnerable groups and specific diseases.

The Combined Approach Matrix as a tool combines five domains of priority setting: research on priority setting methodologies, research and determinants and risk factors, research on policies and cross cutting issues impacting health and health research (e.g. policies, poverty, gender, research, capacity) and research diseases and conditions.

Ronald Labonte and Jerry Spiegel argue that the burden of disease approach may not be sufficient to sustain improvements in health (7). They proposed that health research priorities should be set by integrating the burden of disease and the context in terms of broader “inherent global issues” pertaining to the environment and the prevailing domestic and global social, environmental and economic conditions in which health, disease and health care interventions are embedded (7, 20, 21). At the heart of this approach are some moral issues which can be
a) The need to determine “inherently global issues” i.e those health determining phenomena that transcend national boarders and political jurisdictions.

b) The need to assess how the global economic and political drivers (e.g. macroeconomic policies associated with international finance institutions, liberalisation of trade and investment, global trade agreements and technological innovations are linked to global health issues.

c) How do we locate these global health issues in comprehensive health frameworks such that we enhance identification of specific research questions that are useful to policy makers and civil society? In so doing the results of global health research stand a greater chance to generate knowledge that leads to action.

d) To what extent should research about the burden of health be required to include analysis of inherently global health issues.

Labonte and Spiegel conclude that to minimize the gap between knowledge and action global health research should be prioritized according to the following principles (7).

- Research on inherently global issues that reduce the burden of disease and vice versa.
- Research that presents concerns or questions defined by developing countries.
● Research that increases equity in health outcomes between groups within nations.

● Research that solidly engages civil society and

● Research that increases equity in knowledge capacities between developed and developing countries.

Pang T has proposed an additional principle (8) i.e. “research that is based on sound ethical principles and avoids exploitation of vulnerable populations” He adds that in the post-genomic era, the promotion and upholding of sound ethics is key to ensuring that developing countries benefit fully from the unprecedented knowledge advances of the past decade.

The role of developing countries

The above recommendation should be understood in the context of concerns which have been expressed regarding ethical standards in research carried out in developing countries. Hyder et al found that about a quarter of all human research studies in developing countries do not undergo ethical review in their own country (15). When there is internal review there may be differences in sponsoring and host country reviews (22). Another recent survey of Ethics Committees in Africa has identified a number of important strengths and challenges (23). Developing countries must strive to do better to develop strong and efficient ethics review committees. Uganda has done well in this respect by having fully functional review committees at universities and research institutions. Uganda has also recently revised and updated its national guidelines for research involving human subjects.
"On the other hand ethics review committees in the high income countries may not be conversant with environmental, social and political realities on the ground in low and middle income countries where the research is to be done. This may cause the committees to make ethical reviews which are out of context and make demands which are not only unrealistic but inapplicable and if implemented may lead to a study of questionable ethical standards and also result into social harm in the host community (24).

Many well meaning Foundations, governments, regional and international organisations, universities and research institutions in the north have embraced the concept of global health and global health research. Many publications from developed nations attest to this trend (21, 23, 25, 26). Those of us who live in the developing world are bombarded far too often with requests by people or institutions from all over the world and interested in patternering with us to undertake health research. One may wonder as to who sets the research agenda? In this regard, northern university investigators have set up and are collaborating through extensive world wide research systems which unfortunately in many instances lead to the transfer of large research data sets and biological specimens from the developing world to the developed countries for analysis. And how and by whom is the research agenda set and prioritized? More often than not the available funding opportunities are from the haves of the world and they determine what is relevant for the have-nots and what is to be researched on. Admittedly there is an increasingly albeit slow greater engagement of the have-nots in the process. Regrettably we do not know how to do it better. We need an architecture of global priority setting for health research.
Clearly the efforts for global health research are so far being driven from the north and we are yet to see many meaningful initiatives led from the developing world. As recommended by the commission, global priorities should be anchored and determined from regional priorities and the latter should be informed by national priorities. How can the global health research priorities better reflect the voices of those in greatest need in developing countries and why isn't this the case so far? This is partly a reflection of an existing research capacity gap. Whereas there have been significant advances in priority setting at country level many countries are still challenged by the complexity of the processes, methods and tools needed.

**The national – global schism**

The poor or lack of interface between national and global health research agenda setting is recognised and troubling.

The Bangkok 2000 International Conference on Health Research for development identified some key features of a revitalised health research system. One of these is that “The health research agenda has to be driven by country needs and priorities, within an interactive regional and global network (27).

Nuyens has reminded us that past efforts to identify global priorities for health research have not taken full advantage of existing national research agendas and priorities reconfirming the one
sidedness of global agenda setting (12). He has therefore identified the first challenge facing the health research community as the effort required to change the national-global schism to a national-global interface. The national and global processes of setting priorities should go hand in hand with matching efforts to strengthen (national) research capacities and abilities to translate the research to action.

The global actors need to work closely with national and regional researchers to bring about ongoing and sustainable capacity building programmes which will ensure that the south contributes meaningfully to global priority setting and other research activities. This calls for a re-examination of capacity building approaches by various funders that target an individual scientist versus a combination of individual and institutional capacity development. The developing world population may fail to harness the benefits emanating from global research because of persisting inequities in access to services or products (28). The responsibility of ensuring that developing countries engage meaningfully with developed ones in priority setting is mutually shared between the two parties as each must pro-actively reach out to the other in a genuine and not a cosmetic spirit of partnership. It is extremely encouraging that the “organizations at the forefront of the global health movement are now undergoing both increasing outside scrutiny and internal soul-searching about what they are actually accomplishing” (25).

**Sharing responsibilities in a spirit of partnership**
The role or lack of a role by developing countries is in itself an important consideration in the debate on moral issues and values in setting research priorities for global health. The shift from international to global implies a paradigm shift to health issues that transcend national boundaries and affect the entire world. Therefore both rich and poor nations have a role to play. As reflected by the US office of Global Health Affairs and quoted in the report from the UK’s Chief Medical Officer, “engaging globally in health means working together to share solutions to common problems” (29) If the UK is to protect the UK population, reduce global poverty and harness the opportunities of globalisation UK has to be involved in a global health strategy (12). The US Institute of Medicine has equally emphasized that global health issues are best addressed by cooperative actions and solutions (26). Reducing inequity in health is a global responsibility. How do we best work together without the poor perceiving that they are being exploited and marginalised by the developed countries? How do we prevent a situation where the identified priorities are perceived as serving mainly the interests of the industrialised world? There is potential for tensions to develop between the developed and developing countries if priority setting is not approached in a very collaborative and participatory and transparent manner. Otherwise this may worsen the national-global schism which is characterized by the facts that national research systems (of the south) are hardly contributing to global health research, and that funding, know-how and governance of global health research for development is concentrated in the north.
References


