

**EDITORIAL****TIME TO TAKE COMMUNITY ENGAGEMENT IN RESEARCH SERIOUSLY**Abraham Aseffa, MD, PhD<sup>1</sup>\*

Despite serious challenges (1), health research is expanding in Ethiopia at a relatively rapid rate (2), most of which is epidemiological and clinical, directly linked to data gathering from communities or individuals visiting health facilities (3). The research questions are generally formulated by academics or scientists who design the protocols and approach volunteers to participate in the studies. Researchers drive the agenda of what is investigated.

The participation of communities in research is critical not only to generate knowledge but to also implement lessons learned. In fact, the justification of all the efforts made and expenses incurred in health research is improved health and wellbeing of communities. It is an ethical imperative to verify that benefits outweigh risks and that the research question posed does actually need investigation or can indeed add value. The impact of health research is ultimately impact at the community level.

Scientific advance has led to highly sophisticated systems of knowledge, which require years of training to fully comprehend. The language of science is far detached from the everyday language the average community member would use. Research is by definition an attempt to expand the frontiers of knowledge and is as such forced to apply precise scientific terms to make sure that its findings are comparable with others in the field. On the other hand, study participants cannot engage in research, i.e. participate with genuine understanding, unless the intended protocol is communicated clearly in a language they can understand.

In a country where the adult literacy rate is below 50% (4), proportion of population with at least some high school level of education is just 15.8% (5) and where the burden of disease is mainly borne by the least privileged, the challenge of ensuring comprehension of study protocols by participants is a daunting task. It is however also a task that investigators and their institutions would be expected to have prioritized over the years as part of creating an enabling environment. Unfortunately, this does not seem to be the case for research, unlike for service delivery. Community participation in health care has been on the agenda at least since the Alma Ata Declaration in 1978 (6). Several recommendations, including from the World Health organization (WHO) (7) have emphasized the key role that communities should play in disease control; and initiatives have been undertaken to promote community participation (8). Recent events around Ebola have added further energy to the drive for higher levels of community participation in health care (9).

Health information, to which research contributes, is a key pillar of the health care system and communities are its core stakeholders. The purpose of research is to inform action. It should be widely applied to solve health problems. Evidence based sound practices are badly needed where resources are scarce. A two-way conduit where practice leads to further research would shorten the path to impact. If communities get engaged in exploring ways of improving their own health, “research can serve as a compass to guide innovators” and solutions would likely be implemented faster. WHO TDR has been at the forefront of a global effort to promote social innovation through research, a concept described well in this issue (10).

Not all types of health research would require the same intensity of community participation as implementation research. There is consensus however that communities are major stakeholders in all health research involving human study participants. Ethics guidelines put it clearly that academic interest cannot trump over community interest. Research protocols are reviewed by ethics committees to ensure that this is enforced. The community participation that investigators propose is however often limited to providing information on the research, education on the concepts, clarification of risks and benefits and negotiation to increase enrolment. Community meetings are often held to gain community buy-in and ensure smooth research operations. While this is commendable on its own given the relative paucity of researchers in the country, recent developments (11) indicate that it is time to think of long-term alternatives.

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It is time to make a strategic choice of long-term partnership with communities in the knowledge production process. There is ample evidence from experiences in other countries that community engagement facilitates quality research and improves its impact. On the other hand, in settings where community awareness of research is low or where mistrust is high, misguided and criminal elements can arouse mobs to perpetrate horrendous acts against researchers (11).

Community engagement is a process as much as it is an outcome. It transforms the “politics and power dynamics of research”, and at its best, “embeds it into the local context with leadership by and accountability to people living in the place the research is happening (12).” Engagement is then not for purely instrumental goals but for genuine partnership, with community involvement in the planning, implementation, evaluation and decision-making process. It is an iterative process and grows in stages, from receiving information (where we are at most often), to consultation (where communities act as advisors) and to coordination (where they share decision making authority with academics).

Community engagement can be complex and is time-consuming. In most instances where research is conducted on meagre budget, such as in individual projects of post graduate students, true engagement is unlikely to be achieved within the life time of single projects. Community engagement would rather be the principled choice of academic and research institutions for which adequate investment is allocated and its development proceeds in stages according to a well thought out plan. It should be seen as an integral part of the mainstream activity of research with dedicated staff (including a social scientist), own performance indicators and a monitoring and evaluation plan; which takes time.

Experiences have shown that organized communities can influence the direction, scope and intensity of research when they work closely with researchers, as in HIV/AIDS (13) and tuberculosis Treatment Action Group (14). This can shorten the path and time to institutionalized community engagement. It is rather the norm however that it falls upon the researchers to be proactive and approach communities. Rapid ethics appraisals (15), establishment of community advisory boards, holding discussion sessions and feedback workshops and sincere consultations with the “public wing” of stakeholders (in the balanced score card planning and management system of government institutions) are some of the approaches researchers are employing to work with communities. This experience would contribute to building a favorable attitude towards community engagement in the long-run.

Building a culture of science requires active continuous engagement of researchers with communities. It is vital that communities engage with researchers to benefit from the fruits of science and technology to promote health and wellbeing. Competence in research ethics and community engagement is integral to the mission of academic and research institutions. It is in the interest of government and community development stakeholders to support capacity building in community engagement.

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